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Applying National Cancer Control Indicators to Regional and Remote Cancer Patients' Experiences

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Declarations

Conflict of interest

The authors declare that they have no conflict of interest.

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Ethical Approval

The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of Southern Queensland (Ethics approval number: ref. H17REA152).

Consent to participate

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

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author Contribution Statement

All authors contributed to the study conception and design. Material preparation and data collection were conducted by Belinda Goodwin, Fiona Crawford-Williams, Arlen Rowe, and Leah Zajdlewicz and analyses were performed by Belinda Goodwin and Michael Ireland. The first draft of the manuscript was written by Jeff Dunn and Suzanne Chambers and all authors provided substantial contributions in revising the manuscript. All authors read and approved the final manuscript.

ABSTRACT

Objectives: To examine the health services experience of cancer patients from regional and remote Australia using the Australian National Cancer Control Indicators (NCCI) guidelines as an assessment framework.

Design: Cross-sectional.

Setting: Queensland non-for-profit cancer accommodation lodges.

Participants: Participants were cancer patients who travelled for treatment from rural and remote Queensland to major urban centres (n=518; age $M = 64.6$, SD =11.18).

Outcome measures: Assessments included NCCI patient indicators, quality of life (QoL), psychological distress and unmet supportive care needs.

Results: The frequency at which NCCI indicators were met ranged from 37.5% for receiving an assessment and care plan to 97.3% for understanding explanations about diagnosis. Middle school educated participants were more likely than those with senior level education or higher to receive an assessment and care plan (OR = 1.90, CI = 1.23 – 2.91) and to report having their views on treatment taken into account (OR = 2.22, CI = 1.49 – 3.33). Patients with breast or prostate cancer reported better communication and patient involvement and information and services provision ($r = p < .001$) compared to those with skin and head and neck cancer. When compared to information and service provision, communication and patient involvement showed stronger positive associations with QoL ($z = 2.03$, $p = .042$), psychosocial ($z = 2.05$, $p = .040$), and patient care ($z = 2.00$, $p = .046$) outcomes.

Conclusion: The patient care experience varies across the NCCI indicators by sociodemographic and clinical factors that likely reflects health care system biases. Perceptions about communication and involvement appear most critical for optimal outcomes and should be a priority action area for cancer control.

Keywords: cancer; health service; information; communication; patient experiences; cancer control.

Strengths and limitations of this study

- This large representative sample was recruited from a state-wide jurisdiction and so likely represents the actual experience of patients from regional and remote Australia.
- This study was cross-sectional therefore causality cannot be assumed.
- This study was aimed at gaining an insight into the experiences of regional and remote cancer patients, hence findings are not generalisable to urbanised populations.

INTRODUCTION

In Australia, as in other high income countries, cancer care delivery systems continue to be tested by increasing cancer prevalence due to an aging population and increasing survival. (1) Compounding this, widening socioeconomic and geographic inequities in cancer outcomes, (2) increasing healthcare costs, and workforce shortages (3,4) are all exacerbated by rapidly expanding, and complex, cancer diagnostic and treatment options. (5) In response, national societies and cancer control agencies globally have developed frameworks and guidelines for quality care cancer services that typically include characteristics such as being person-centered and tailored, evidence-based, coordinated, multi-disciplinary, quality assured and accountable. (6–9) While many of these guidelines focus on treatment, supportive and psychosocial care is also a central feature. For example, the first (of eight) recommendations from the Institute of Medicine 2013 report centers on patients and families receiving understandable information about all aspects of their cancer care. (8) The Australian Government's guides to best-practice cancer care, the Optimal Cancer Care Pathways, list access to supportive care, including survivorship, as a key theme across all steps of the care pathway. (7) Similarly, risk stratified pathways of cancer care in the UK emphasize assessing and supporting holistic patient needs, including those that are psychosocial and spiritual. While such frameworks are important, the question arises as to how cancer services might best evaluate the extent to which cancer care is meeting these recommendations, where gaps most exist, and crucially who is more vulnerable to underservicing.

A number of groups have developed indicators to reflect the extent to which optimal care is being delivered in terms of information, communication, education and care-coordination during diagnosis and treatment. (10,11) Thus far this been for quality assurance purposes within administering jurisdictions with findings not generally presented within the peer-reviewed literature. A set of items was recently developed by Cancer Australia for

monitoring cancer patient experiences at the national level. The National Cancer Control Indicators (NCCI) patient experiences items are based on the National Health Service (NHS) England Cancer Patient Experience Survey, (12) and reflect the receipt and understanding of information about diagnosis and side effects of treatment as well as patient involvement in care and decision making, and the provision of care co-ordination tools and services. To date, results from the Australian NCCI indicators for patient experience have not been reported.

It is especially important to consider the quality of the patient experience for people who live in geographically remote locations. People with cancer living in remote locations incur the additional burden of having to travel long distances to attend specialist treatment facilities that are not available in sparsely populated and geographically remote areas of the country. (13) Cancer patients who live outside of major cities in Australia are known to experience poorer cancer outcomes (14,15) and report poor physical and mental health, (16,17) lower quality of life (QoL) (18,19) and unmet supportive care needs (18,20,21) compared to their urban counterparts.

Accordingly, the present study applied the NCCI guidelines as a framework to examine the health services experience of cancer patients and their families from regional and remote Australia experiencing geographic dislocation while obtaining cancer treatment. In doing so: 1) the construct validity of the NCCI guidelines was examined, 2) the extent to which these guidelines are currently being met was tested, 3) sociodemographic predictors of underservicing were explored, and 4) how psychosocial outcomes, unmet supportive care needs, satisfaction with health care were related to underservice were described.

METHOD

Patient and Public Involvement Statement

Patient and public involvement in the design and conduct of the study was sought from community members, research volunteers, and pilot study participants. Several community members including cancer survivors living in rural areas reviewed interview and

questionnaire items providing feedback on the clarity, formatting, and time to complete. The research volunteers tested and evaluated materials and protocols while patients provided written and verbal feedback to researchers regarding clarity, burden and relevance associated with completing study materials. Minor refinements to the study materials to were made to increase clarity and ease of delivery based on this feedback.

Participants

Participants (n = 518) were cancer patients from regional and remote Queensland staying at six Cancer Council Queensland (CCQ; a cancer control not-for-profit) lodges providing low or no - cost accommodation while receiving cancer care. Figure 1 depicts participant recruitment flow. Eligibility criteria were: 18 years or older, able to read and understand English, and staying at a CCQ lodge for cancer treatment. A total of 1405 of 1801 eligible CCQ lodge guests staying between September 11th, 2017 and 1st February, 2020 were provided with an invitation pack containing study details, consent forms and a questionnaire. Three hundred and ninety-six eligible guests were not approached as contact details were not provided or accurate.

Invitation packs were distributed upon arrival by lodge staff or, if this was not possible (e.g., after hours check-in) were sent via mail to their home address. Patients were contacted by phone one week after pack distribution, offered further details and invited to participate. Assessments included a self-administered questionnaire and face-to-face (or telephone) interview at baseline, followed by self-administered questionnaires at 3 months, 12 months and annually thereafter.

Of the eligible patients who received an invitation pack (n=1405), 635 (45.2%) consented to participate, 395 (28.1%) actively refused, and 375 (26.7%) did not return a consent form and could not be re-contact-ed. This report focusses on data collected at baseline for a sample of 518 consenting participants who completed both the questionnaire and interview component of the study.

Materials and measures

Questionnaires assessed demographic and patient characteristics, patient experiences according to the NCCI, psychological distress and cognitive adjustment, satisfaction with healthcare, QoL, and supportive care needs. Structured interviews assessed diagnostic and treatment pathways. The study has approval from a recognized institutional Human Research Ethics Committee (ref. H17REA152).

Demographics and patient characteristics

Site of current cancer, gender, age, country of birth, highest level of education, and household income were reported by each participant. Participant's residential street address at baseline was geocoded and mapped to the 2011 SA2 boundaries using MapMarker® Australia Version 15.16.0.21 and MapInfo Pro® Version 15.0 and classified by Remoteness Area (22) and Socio-Economic Indexes for Areas (SEIFA). (23) Most recently diagnosed primary cancer site was obtained via self-report and verified against the population-based Queensland Cancer Register (QCR). Self-report data were relied upon where diagnosis could not be verified by the QCR (n=39), for example if the patient had non-melanoma skin cancer (which is not routinely notified to registries in Australia) or the patient's diagnosis had not yet been notified to the QCR.

National Cancer Control Indicators - patient experience

Eight items derived from the National Health Service (NHS) England Cancer Patient Experience Survey (10) were adapted by Cancer Australia (12) as measures of National Cancer Control Indicators (NCCI) of cancer patient experiences. The items captured four key elements including 1) Patient information, communication and education during diagnosis; 2) Patient information, communication and education during; 3) Patient co-ordination and integration of care, continuity and transition; 4) Respect for patient preference. Response scales for each item vary including 3 category (e.g., yes, no, I don't know/remember) and 4 category (e.g., yes, yes to some extent, no, I don't know/remember) response options.

Responses to each NCCI item were collapsed into a yes/no binary response with those responding with “I don’t know” or “I don’t remember” coded as missing. Full item wording, response categories and method for collapsing responses is available in as supplementary material (Supplementary Table 1).

As the NCCI items have not been validated for use in research an exploratory factor analysis was conducted for the current sample. One to four-factor solutions were extracted sequentially using Mplus v.8 software. (24).The decision on the number of factors to retain was driven by 1) overall and comparative model fit (determined by χ^2 and $\Delta\chi^2$ and their corresponding p values), 2) balancing the trade-off between explanatory power and parsimony (determined by the Bayesian and the Akaike information criteria), and 3) an interpretable pattern of strong and non-cross-loading factor loadings.

For the one to three-factor solutions, overall model fit improved as a function of the number of factors extracted (see Table 1). However, the four-factor solution yielded a poorer fit than the three-factor solution according to both χ^2 and information criteria values and was not considered a candidate solution. The Bayesian information criterion shows that the three-factor solution exhibited poorer fit compared to the two-factor solution once model complexity was accounted for. Therefore, the two-factor solution represented the best trade-off of explanatory power and parsimony. Finally, the two-factor solution also yielded a simple structure in the pattern of item loadings. Each NCCI item loaded cleanly onto one of each of the two factors (see Table 2); the first reflecting effective communication and patient involvement the second reflecting the provision of information or services. A confirmatory factor analytic approach was used to calculate factor score variables for the communication and patient involvement and provision of information and services. Factor score variables were transformed so that scores ranged from 0 (low) to 1.68 (high) for the communication and patient involvement factor and 0 (low) to 1.84 (high) for the provision of information and services factor.

Table 1. Comparative fit statistics for one to four factor EFA solutions

	1-factor	2-factor	3-factor	4-factor
AIC	3848.70	3784.24	3775.34	3787.09
ΔAIC	-	64.46	8.89	-11.74
BIC	3916.70	3881.99	3898.59	3931.59
ΔBIC	-	34.71	-16.61	-32.99
χ^2 (*p*)	435.96 (< .001)	306.55 (.001)	207.71 (.776)	225.45 (.368)
$\Delta\chi^2$ (*p*)	-	84.76 (< .001)	40.37 (< .001)	($\Delta\chi^2$ is negative)

Table 2. Exploratory factor analysis item loadings for two-factor solution

Item	**Communication and patient involvement**	**Provision of information and services**
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	**0.884***	0.005
Were you involved as much as you wanted to be in decisions about your care and treatment?	**0.925***	-0.063
Were the possible side effects of treatment(s) explained in a way you could understand?	**0.507***	0.249*
When you were told you had cancer, did you understand the explanation of what was wrong with you?	**0.633***	0.059
Have you been offered a written assessment and care plan?	0.185	**0.579***
When you were told you had cancer, were you given written information about the type of cancer you had?	0.075	**0.579***
Before you started your treatment, were you given written information about the side effects of treatment(s)?	0.002	**0.719***
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	-0.001	**0.736***

Geomin Rotated Loadings (* significant at 5% level)

Psychological distress and adjustment

Stress, anxiety and depression were measured using the 21-item Depression, Anxiety, and Stress Scale (DASS-21) (25). The scale asks respondents to indicate the degree to which each statement applied to them over the past week on a four-point Likert scale ranging from 0 = *not at all* to 3 = *almost always*. Scores for each subscale were summed and multiplied by 2, with higher scores indicating more distress. (26) Reliability for the anxiety (α = .67), stress (α = .87) and depression (α = .90) subscales were adequate to excellent.

Psychological adjustment to a cancer diagnosis was assessed using the Constructed Meaning Scale **(**CMS). The 8 item CMS measures a patients' cognitive response to being diagnosed with a life-threatening illness (27) on a 4-point Likert scale ranging from 1 = *strongly disagree* to 4 = *strongly agree*. Scores on the CMS reflect ability to construct a positive outlook regarding the effect that cancer has or will have on their future, their relationships, and their sense of self. Internal consistency in the current study was good (α = .77).

Satisfaction with healthcare

Nine items were created by the researchers to assess patients' satisfaction with their health care in terms of the referral process, speed of diagnosis, speed of test results, the hospital where they were treated and the doctors and nurses, the emotional and physical support they receive in hospital and finally, and their medical care overall. Degree of satisfaction with each item was reported on a 5-point Likert scale ranging from 1 = *very dissatisfied* to 5 = *very satisfied*. Data and participant feedback from the pilot phase were examined to ensure items were clear and relevant and excellent internal consistency for the measure was evident (α = .92). Items were averaged to create a mean score.

Quality of life

Multidimensional QoL was measured using the 35-item Assessment of Quality of Life 8 Dimension instrument (AQoL-8D)(28). Participants responded on a 5-point Likert scale based on aspects of QoL during the past week. Responses are coded so that lower scores reflect poorer QoL on two psychometrically derived dimensions reflecting physical and psychological wellbeing. Internal reliability was evident for physical (α = .64) and psychological (α = .92) dimensions in the current study.

Supportive care needs

Unmet need was measured using the Supportive Care Needs Survey Short Form-34 (SCNS-SF34). (29) The scale assesses patient need for support across five domains including physical and daily living, psychological, health systems and information, patient care and support, and sexuality with a single item regarding financial needs. Responses were coded: 0 (*no need/not applicable/need satisfied*), 1 (*low need*), 2 (*moderate need*), or 3 (*high need*) and means calculated resulting in six continuous variables reflecting the degree of need in each domain. Subscales showed excellent internal reliability (physical and daily living needs α = .86; psychological needs α = .94; health system and information needs α = .95; patient care and support needs α = .88; sexuality needs α = .87).

Analysis

Data analyses were carried out in SPSS Version 26. (30) Frequencies and percentages were calculated for patient responses to each NCCI item. Demographics and area-level characteristic differences in the likelihood of reporting *yes* to a NCCI item were examined using chi-square statistics. A family-wise error rate adjustment was applied to constrain the chance of Type 1 errors to 5%. One-way analyses of variance (ANOVA) were used to identify group differences in NCCI factor scores. Pearson's point biserial correlations assessed whether age was associated with NCCI items and factors. Where group differences were significant, post-hoc contrasts were applied to compare each category against others.

Odds ratios (OR) and 95% confidence intervals (CI) were reported for contrasts involving NCCI items. Associations between factor scores and health/psychosocial variables were assessed using a series of correlations with coefficients graphed and compared using a Fisher's *z*-test. Missing data were excluded from analyses in a pairwise manner.

RESULTS

Sample characteristics

Participant ages ranged from 26 to 93 (M = 64.6 , SD = 11.18) and 47.3% of participants identified as female and 52.7% as male. Most participants were born in Australia (80.5%), with the remainder born in the UK (9.9%), New Zealand (4.7%), and other countries (4.9%). Most participants reported low income with 64.8% reporting a household income under $50,000 a year (i.e., the median yearly gross income in Australia). Most patients were not fully covered by private health insurance (81.5%) and the majority lived in inner (44.0%) or outer (42.5%) regional areas marked by high levels of socio-economic disadvantage (i.e., 66.5% were in the lowest socio-economic quintiles). The most common primary cancers were breast (19.3%), head and neck (14.3%), and skin (12.6%). – see Table 3. Referenced to population statistics (31), the current sample was representative of the non-metropolitan Queensland cancer population in terms of gender, age, and country of birth. However, patients with skin cancer were under-represented (24.5% in population) and patients with head and neck cancer were over-represented (5.8% in population). At the time of data collection, time since diagnosis for each participant ranged between and 33.7 years and 1 day (Median = 211), with 64% of participants diagnosed within the previous 12 mont

Table 3. Participant characteristics and responses to NCCI items with chi-square and ANOVA group comparisons.

		Communication and patient involvement					**Provision of information and services**				
	Total n (%)^	Views on treatment n (%)	Involved in decisions n (%)	Side effects explained n (%)	Understand Explanation n (%)	Factor Score M (SD)	Written info on type of cancer n (%)	Assessment and care plan n (%)	Clinical nurse support n (%)	Written info on side effects n (%)	Factor Scor M (SD)
Gender		$\chi^2 = 2.69$	$\chi^2 =1.30$	$\chi^2 = 0.32$	$\chi^2 =0.10$	$F = 2.15$	$\chi^2 =7.88$*	$\chi^2 =0.23$	$\chi^2 =1.05$	$\chi^2 =1.46$	$F = 2.92$
Female	**245 (52.7%)**	147 (63.4%)	149 (63.4%)	156 (65.5%)	234 (97.5%)	1.17 (0.43)	163 (70.3%)	73 (36.3%)	157 (71.7%)	199 (86.9%)	1.36 (0.46
Male	**273 (47.3%)**	147 (56.1%)	165 (58.4%)	182 (67.9%)	263 (97.0%)	1.11 (0.43)	152 (58.2%)	86 (38.6%)	160 (66.4%)	209 (82.9%)	1.21 (0.48
Education		$\chi^2 = 16.61$*	144 (68.2%)	$\chi^2 = 9.70$*	$\chi^2 = 0.84$	$F = 9.24$	$\chi^2 = 3.00$	$\chi^2 = 11.44$*	$\chi^2 = 6.39$	$\chi^2 = 2.65$	$F = 7.46$*
Middle school (yr 10)	**217 (42.3%)**	146 (70.2%)	41 (55.4%)	155 (73.1%)	205 (96.7%)	1.23 (0.42)	141 (68.1%)	85 (47.0%)	141 (75.8%)	176 (86.7%)	1.27 (0.48
Senior school (yr 12)	**78 (15.1%)**	39 (53.4%)	117 (55.2%)	41 (53.9%)	76 (98.7%)	1.05 (0.42)	44 (57.9%)	17 (28.3%)	47 (64.4%)	55 (78.6%)	1.07 (0.47
Trade/Tertiary	**218 (42.5%)**	107 (51.4%)	$\chi^2 = 0.06$	139 (65.3%)	211 (97.2%)	1.08 (0.42)	128 (62.4%)	57 (31.8%)	127 (64.8%)	172 (84.7%)	1.12 (0.46
> median income		$\chi^2 = 0.03$	182 (59.7%)	$\chi^2 = 0.06$	$\chi^2 = 2.17$	$F = 0.09$	$\chi^2 = 0.24$	$\chi^2 = 0.44$	$\chi^2 = 1.46$	$\chi^2 = 1.66$	$F =0.01$
Yes	**318 (65.3%)**	73 (57.5%)	144 (68.2%)	84 (67.2%)	126 (99.2%)	1.14 (0.40)	81 (65.3%)	37 (34.9%)	77 (66.4%)	103 (88.8%)	1.17 (0.47
No	**169 (34.7%)**	172 (58.3%)	78 (60.9%)	204 (66.0%)	301 (96.8%)	1.13 (0.44)	189 (62.8%)	100 (38.6%)	200 (72.5%)	248 (83.8%)	1.17 (0.48
Born in Australia		$\chi^2 = 0.01$	$\chi^2 = 0.15$	$\chi^2 =0.59$	$\chi^2 = 1.62$	$F =0.18$	$\chi^2 =0.55$	$\chi^2 = 0.15$	$\chi^2 =0.43$	$\chi^2 = 0.85$	$F = 0.02$
Yes	**413 (80.5%)**	233 (59.6%)	238 (60.3%)	261 (65.6%)	387 (96.8%)	1.32 (0.44)	246 (63.2%)	127 (38.0%)	248 (69.5%)	322 (85.4%)	1.17 (0.48
No	**100 (19.5%)**	58 (59.8%)	63 (62.4%)	71 (69.6%)	104 (99.0%)	1.15 (0.42)	66 (67.3%)	30 (35.7%)	64 (66.0%)	80 (81.6%)	1.16 (0.45
Full PHI cover		$\chi^2 = 0.86$	$\chi^2 = 0.44$	$\chi^2 = 0.10$	$\chi^2 = 0.96$	$F = 0.26$	$\chi^2 = 0.32$	$\chi^2 = 0.05$	$\chi^2 = 3.38$	$\chi^2 = 0.85$	$F = 0.01$
Yes	**91 (18.5%)**	55 (64.7%)	56 (64.4%)	57 (65.5%)	85 (98.8%)	1.16 (0.24)	55 (67.1%)	27 (36.0%)	48 (60.0%)	73 (88.0%)	1.17 (0.47
No	**400 (81.5%)**	224 (59.3%)	233 (60.5%)	261 (67.3%)	380 (96.9%)	1.37 (0.44)	242 (63.7%)	120 (37.4%)	247 (70.6%)	308 (83.9%)	1.17 (0.48
Cancer Site		$\chi^2 = 4.97$	$\chi^2 = 8.65$	$\chi^2 = 2.59$	$\chi^2 = 1.37$	$F = 2.29$*	$\chi^2 = 29.65$*	$\chi^2 = 2.81$	$\chi^2 = 46.11$*	$\chi^2 = 17.43$*	$F = 8.03$*
Breast	**100 (19.3%)**	65 (68.4%)	66 (68.0%)	60 (61.9%)	97 (98.0%)	1.23 (0.43)	78 (80.4%)	33 (41.3%)	87 (92.6%)	84 (92.3%)	1.36 (0.39
Skin	**65 (12.6%)**	38 (59.4%)	32 (50.8%)	39 (61.9%)	62 (95.4%)	1.05 (0.46)	29 (44.6%)	19 (34.5%)	27 (48.2%)	43 (69.4%)	0.97 (0.54
Head & Neck	**74 (14.3%)**	39 (54.2%)	48 (66.7%)	51 (68.9%)	71 (97.3%)	1.14 (0.42)	37 (52.9%)	26 (44.8%)	39 (66.1%)	60 (85.7%)	1.16 (0.48
Prostate	**64 (12.3%)**	38 (62.3%)	43 (67.2%)	43 (68.3%)	62 (98.4%)	1.20 (0.41)	47 (75.8%)	20 (37.7%)	47 (81.0%)	49 (80.3%)	1.25 (0.45
Other	**215 (41.5%)**	114 (56.4%)	116 (56.3%)	145 (69.4%)	205 (97.2%)	1.10 (0.24)	124 (62.3%)	61 (34.3%)	117 (60.6%)	172 (87.3%	1.12 (0.46
TOTAL	**518 (100%)**	294 (59.5%)	305 (60.8%)	338 (66.8%)	498 (97.3%)	1.14 (0.43)	316 (64.0%)	159 (37.5%)	317 (68.9%)	408 (84.8%)	1.17 (0.47

PHI – Private Health Insurance. n (%) = number and percentage of participants in each demographic category responding yes to item, M (SD) = Mean and SD reported for factor scores, ^ valid percent calculated based on non-missing responses to this item, *= $p < .05$ (applying family-wise error rate adjustment for multiple χ^2 tests)

Table 3 cont. Participant characteristic and responses to NCCI items with chi-square and ANOVA group comparisons.

		Communication and patient involvement					**Provision of information and services**				
	Total n (%)	Views on treatment n (%)	Involved in decisions n (%)	Side effects explained n (%)	Understand explanation n (%)	Factor Score M (SD)	Written info on type of cancer n (%)	Assessment and care plan n (%)	Clinical nurse support n (%)	Written info on side effects n (%)	Factor Score M (SD)
SEIFA Quintile		$\chi^2 = 5.29$	$\chi^2 = 3.45$	$\chi^2 = 4.04$	$\chi^2 = 4.59$	$F = 0.61$	$\chi^2 = 1.30$	$\chi^2 = 0.90$	$\chi^2 = 5.58$	$\chi^2 = 2.64$	$F = 0.41$
1st (lowest)	**185 (36.0%)**	115 (64.2%)	110 (60.8%)	129 (71.3%)	180 (98.4%)	1.17 (0.43)	113 (63.8%)	56 (37.3%)	118 (71.1%)	154 (88.0%)	1.20 (0.46)
2nd	**155 (30.3%)**	89 (60.5%)	93 (61.2%)	99 (65.6%)	147 (96.1%)	1.12 (0.45)	98 (65.8%)	49 (38.9%)	90 (65.7%)	122 (82.4%)	1.16 (0.49)
3rd	**112 (21.9%)**	59 (57.3%)	59 (56.75)	65 (60.2%)	105 (95.5%)	1.09 (0.44)	66 (63.5%)	36 (40.9%)	71 (72.4%)	82 (83.7%)	1.17 (0.49)
4th	**54 (10.6%)**	25 (47.2%)	37 (69.8%)	37 (68.5%)	54 (100.0%)	1.12 (0.39)	32 (59.3%)	17 (34.7%)	31 (64.6%)	42 (82.4%)	1.13 (0.48)
5th (highest)	**5 (1.0%)**	3 (60.0%)	2 (40.0%)	3 (60.0%)	5 (100.0%)	1.04 (0.43)	4 (80.0%)	1 (25.0%)	1 (25.0%)	3 (75.0%)	1.02 (0.041)
ARIA		$\chi^2 = 5.22$	$\chi^2 = 3.35$	$\chi^2 = 4.55$	$\chi^2 = 2.66$	$F = 0.48$	$\chi^2 = 0.99$	$\chi^2 = 4.67$	$\chi^2 = 2.47$	$\chi^2 = 0.94$	$F = 0.99$
Major city	**24 (4.7%)**	9 (37.5%)	14 (58.3%)	13 (54.2%)	24 (100.0%)	1.03 (0.44)	17 (70.8%)	10 (41.7%)	14 (63.6%)	20 (90.9%)	1.17 (0.46)
Inner regional	**225 (44.0%)**	128 (60.7%)	140 (63.6%)	154 (70.3%)	216 (97.3%)	1.15 (0.38)	139 (64.7%)	61 (33.5%)	133 (68.6%)	177 (83.5%)	1.16 (0.44)
Outer regional	**217 (42.5%)**	128 (61.0%)	125 (60.4%)	140 (65.7%)	207 (96.3%)	1.12 (0.47)	129 (62.3%)	76 (43.4%)	134 (68.0%)	172 (85.1%)	1.19 (0.52)
Remote	**23 (4.5%)**	13 (61.9%)	12 (54.5%)	14 (66.7%)	23 (100.0%)	1.14 (0.44)	13 (61.9%)	7 (38.9%)	14 (66.7%)	16 (84.2%)	1.17 (0.50)
Very remote	**22 (4.3%)**	13 (61.9%)	10 (45.5%)	12 (54.5%)	21 (100.0%)	1.08 (0.43)	15 (68.2%)	5 (27.8%)	16 (84.2%)	18 (85.7%)	1.18 (0.48)

n(%) = number and percentage of participants in each area-level category responding yes to item, M (SD) = Mean and SD reported for factor scores,
*= $p < .05$ (applying family-wise error rate adjustment)

Communication and patient involvement

Participants reported that their views were taken into account when their team of doctors and nurses were discussing their treatment 59.5% of the time (Table 3). Those with middle school education or lower were twice as likely to report having their views taken into account in treatment decisions (OR = 2.22, CI = 1.49 – 3.33) compared to those with senior high school or trade/tertiary level education. Older patients were slightly more likely to report that their views were taken into account by doctors and nurses when deciding on treatment ($r = .11$, $p = .02$). Similarly, 60.8% of participants felt they were involved in decisions about their care and treatment as much as they would have liked, however, this did not vary according to individual characteristics.

Most participants reported understanding the explanation of "what was wrong with them" upon diagnosis (97.3%) and this did not differ significantly according to individual characteristics. Most patients (66.8%) reported that the possible side-effects of their treatment were explained to them in a way they could understand. Those with middle school education or lower were 1.5 times more likely to report having side effects explained to them in a way that they understood compared to those with trade/tertiary level education (OR = 1.50, CI = 1.14 – 1.96) and those with senior level education were less likely to report this compared to those with trade/tertiary level education (OR = 0.65, CI = 0.46 – 0.90).

Group differences were evident in participants' scores on the communication and patient involvement factor with patients possessing middle school level education (M = 1.23, SD = 0.42) reporting higher scores than those with trade/tertiary level education (M = 1.08, SD = 0.42), t (509) = 42.75, $p < .001$, $d = 0.36$, or those with senior school level education (M = 1.05, SD = 0.42), t (509) = 21.88, $p < .001$, $d = 0.43$. When compared with all other cancer types, patients with breast (M = 1.23, SD = 0.43), t (512) = 28.75, $p < .001$, $d = 0.28$, and prostate (M = 1.20, SD = 0.41), t (512) = 22.40, $p < .001$, $d = 0.17$ cancer reported higher

scores on the communication and patient involvement factor, while those with skin (M = 1.05, SD = 0.46), t (512) = 19.75, *p* <.001, *d* = 0.22 and head and neck (M = 1.14, SD = 0.42), t (512) = 22.83, *p* <.001, *d* = 0.01 cancers reported lower scores than those with other cancer types.

Provision of information and services

Sixty-four percent of participants were given written information about the type of cancer they had. Females were 1.69 (CI = 1.16 – 2.46) times as likely to report receiving this information when compared to males. Patients with breast cancer were 2.41 (CI = 1.39 – 4.42) times more likely, and those with skin cancer were 0.49 (CI = 0.28 – 1.18) times as likely to receive written information about the type of cancer they had compared to those with other cancers. The majority of patients reported being given written information about the side effects of treatment (84.8%) with those with skin cancer less likely to receive this information compared to those with other cancer types 0.33 (CI= 0.17 – 0.65).

Only 37.5% of participants reported receiving a written assessment and care plan. Those with middle school education or lower were almost two times more likely to report receiving an assessment and care plan (OR = 1.90, CI = 1.23 – 2.91) compared to those with senior high school or trade/tertiary level education. Over two thirds of patients reported being given the name of a clinical nurse specialist to support them through treatment (68.9%), however, patients with breast cancer were 8.07 (CI = 3.55 – 18.37) times more likely, and patients with prostate cancer patients were 2.77 (CI = 1.36– 5.68) times more likely, to be offered this service compared to participants with other types of cancer.

Those with middle school level education or lower (M = 1.27, SD = 0.48) reported higher scores on the provision of service and information factor than those with trade/tertiary level education (M = 1.12, SD = 0.47), t (509) = 39.71, *p* <.001, *d* = 0.32 or those with senior school level education (M = 1.07, SD = 0.46), t (509)= 20.28, *p* <.001, *d* = 0.42. When compared with all other cancer types, patients with breast (M = 1.36, SD = 0.39), t (99) =

34.47, *p* <.001, *d* = 0.54 or prostate (M = 1.25, SD = 0.45), t (63) = 22.42, *p* <.001, *d* = 0.19 cancer reported higher scores on the provision of information and services factor, while those with skin (M = 0.97, SD = 0.54), t (64) = 14.52, *p* = <.001, *d* = 0.46 or head and neck (M = 1.16, SD = 0.48), t (73) = 20.73, *p* <.001, *d* = 0.03 cancers reported lower scores than those with other cancer types. Area-level characteristics (i.e., remoteness or SEIFA) were not significantly associated with single items or factor scores reflecting provision of information and services (see Table 3).

Associations between NCCI factor scores and health and psychosocial variables

Both communication and patient involvement and provision of information and services factors shared significant positive associations with QoL, satisfaction with health care and constructed meaning (see Figure 2). They were also both associated with lower supportive care needs in most cases, the strongest associations being with health system and information needs. The communication and patient involvement factor was moderately associated with greater psychosocial QoL (*r* = .30, *p* <.001) and satisfaction with healthcare (*r* = .29, *p* <.001) as well as lower levels of unmet 'health systems and information' (*r* = -.39, *p* <.001). and 'patient care' (*r* = .35, *p* <.001) needs and lower cancer threat appraisal (*r* = .31, *p* <.001). The provision of information and services factor had a weaker pattern of associations though still moderately predicted lower levels of unmet 'health systems and information' (*r* = -.32, *p* <.001) and 'patient care' (*r* = -.23, *p* <.001) needs as well as greater satisfaction with healthcare (*r* = .23, *p* <.001). The communication and patient involvement factor shared significantly stronger associations with higher psychosocial QoL (*z* = 2.03, *p* = .042), and lower levels of unmet need in terms of psychosocial support (*z* = 2.05, *p* =.040) and patient care (*z* = 2.00, *p* =.046). Communication and patient involvement was associated with lower stress and anxiety, while provision of information and services was not (see Figure 2).

Area-level characteristics (i.e., remoteness or SEIFA) were not significantly associated with single items or scores on either NCCI factor (see Table 3).

DISCUSSION

The goal of delivering equitable patient-centered cancer care is a corner stone of cancer control plans and care guidelines. (6,7,9,12) The present study suggests that the NCCI patient experience indicators have validity and strong potential as a quality assurance tool to support this. Importantly, this brief tool discriminated between different aspects of patient experience for those dislocated from their home during treatment and identified characteristics associated with a poorer experience. While it was almost universal for patients to recall understanding the explanation of their treatment, and most people reported that treatment side effects were explained and supported with written information, only a minority received a written assessment and care plan. Further, patient experience varied by clinical and sociodemographic characteristics suggesting that there is work to be done on better understanding what influences care, and how we might intervene.

From a construct perspective, the patient experience as measured by the NCCI indicators presented along two key dimensions: 1) communication and patient involvement and 2) provision of information and services. For both dimensions, the strong association with health system and information needs provides evidence of convergent validity. The closer connection between communication and patient involvement and QoL and psychosocial outcomes intuitively makes sense given the important role of the interpersonal relationships between the health care teams and patients, as well as the self-efficacy and personal agency that evolves from patient's involvement in their health care. (32) These associations may be bi-directional. Patients with lower psychological distress have a higher capacity to absorb information, take part in decision making, benefit from communications with healthcare professionals (33,34) and are subsequently more likely to report satisfaction with this element of their care. (35) Those individuals who are psychologically vulnerable or have poorer QoL likely need stepped up care to achieve optimal outcomes. (36)

Notably, breast and prostate cancer patients were more likely to receive clinical nurse support compared to skin and head and neck cancer patients. This may reflect the early introduction of the specialist nurse role for breast cancer patients, (37) and more recently prostate cancer patients. (38) While a specialist nurse appears to greatly enhance patient experience, (39) providing this for all cancer types is likely a resourcing challenge especially for regional and remote health services. Models that incorporate telehealth and that span broadly across multiple cancer types or chronic disease may be needed. (40) Higher education appeared to be associated with less communication and patient involvement and information and services. The reasons for this are unclear however it may be that health professionals assume these patients require less support or alternatively that people with more education have greater expectations in this domain of care.

As the aim of the present study was to provide specific insight into the experiences of regional and remote cancer patients, caution should be in applied in generalising these findings to urbanised populations. Since the survey is cross-sectional we cannot assume causality; and the data is self-reported and was not able to be verified by observational data or care records. However, this large, representative sample was recruited from a statewide jurisdiction and so likely represents the actual experience of patients from regional and remote Australia.

The present results outline the patient experience for a rural and regional population who are at risk of fragmented or poorly coordinated care. Patients who report better communication with their health care team and more involvement have better QoL, less stress and anxiety, and lower threat. Fulfilling the NCCI indicators connects to lower unmet need in health services and information. Cancer care services that ensure these indicators are met are better placed to provide an optimal cancer experience and improved patient-reported outcomes.

The NCCI presents as a useful and valid tool for assessing the patient experience. The aspect of care that appears most crucial is communication and involvement with the health care team. Strategies to optimize this for regional and remote patients need to be a cancer control priority.

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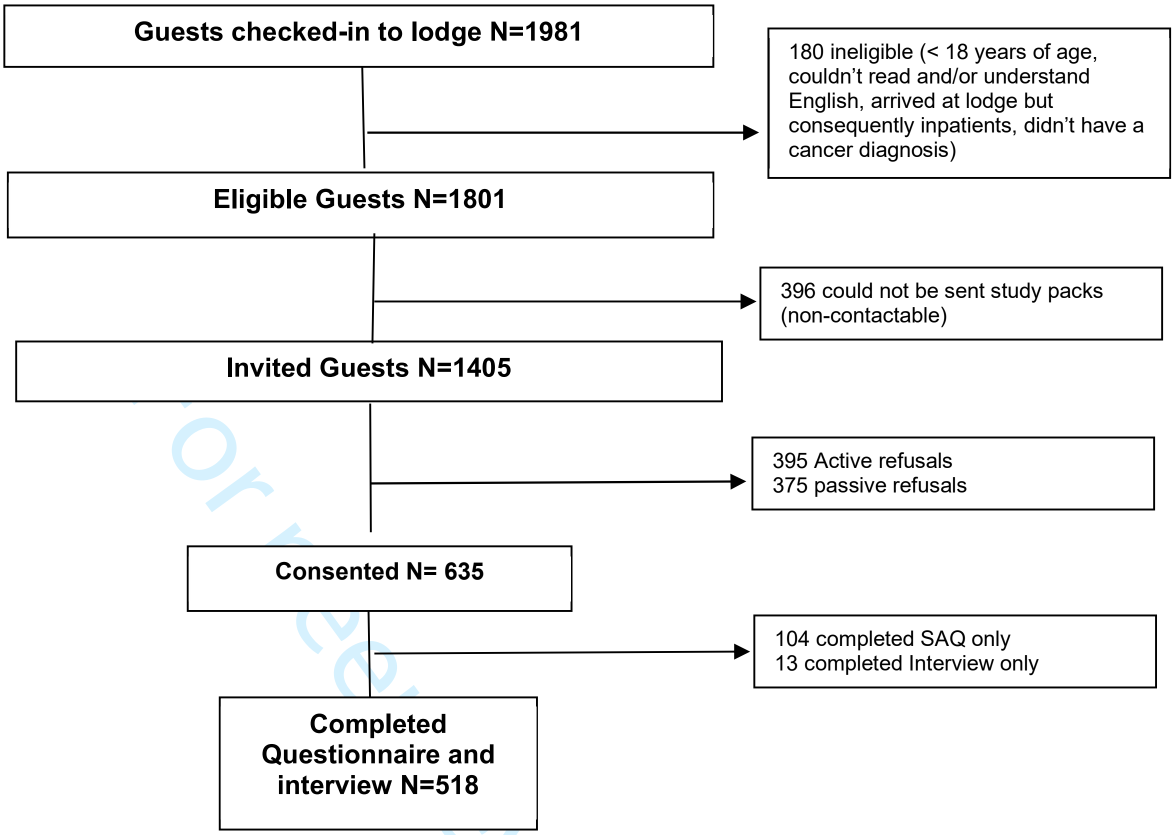
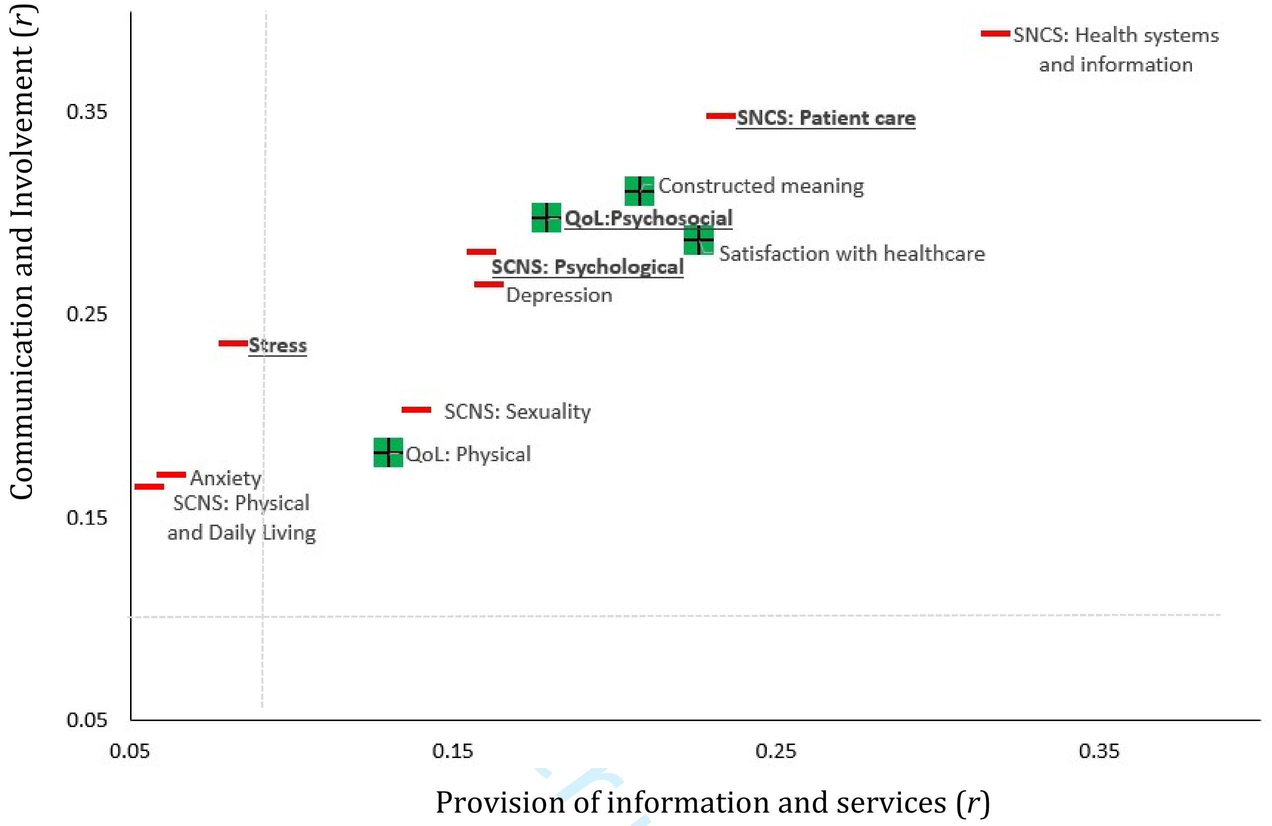
Figure 1. Recruitment flowchart





🟩 = Positive relationship with factor, ▬ = Negative relationship with factor, **<u>bold underlined</u>** = significantly higher association with variable and communication and involvement factor, - - = point at which beta weight is significant at <.05

Figure 2. Visual comparison of the correlation co-efficients between each health/psychosocial variable and each factor.

Applying National Cancer Control Indicators to Regional and Remote Cancer Patients' Experiences (Journal of Cancer Survivorship).

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Supplementary Table 1. Frequencies and percentages^ of responses to NCCI – Patient Experience Items and grouping of binary responses.

	Yes, I completely understood it	**Yes, I understood some of it**	**No**	**I can't remember**	
When you were told you had cancer, did you understand the explanation of what was wrong with you?	345 (66.7%)	153 (29.4%)	14 (2.7%)	5 (1.0%)	
	Yes, and it was easy to understand	**Yes, and it was difficult to understand**	**No**	**I did not need written information**	**I don't know/ can't remember**
When you were told you had cancer, were you given written information about the type of cancer you had?	262 (51.3%)	54 (10.6%)	134 (26.2%)	44 (8.6%)	17 (3/3%)
	Yes	**No**	**I don't know/ can't remember**		
Have you been offered a written assessment and care plan	159 (31.0%)	265 (51.7%)	89 (17.3%)		
	Yes	**No**	**I don't know/ can't remember**		
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	317 (61.8%)	143 (27.9%)	53 (10.2%)		
	Yes, definitely	**Yes, to some extent**	**No, but I would have liked to be more involved**	**I don't know/can't remember**	
Were you involved as much as you wanted to be in decisions about your care and treatment?	305 (59.2%)	161 (31.3%)	36 (6.9%)	13 (2.5%)	
	Yes, definitely	**Yes, to some extent**	**No**	**I didn't know my treatment was being discussed …**	
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	294 (57.8%)	152 (29.2%)	31 (6.1%)	17 (2.9%)	
	Yes, definitely	**Yes, to some extent**	**No**	**I did not need an explanation**	**I don't know/ can't remember**
Were the possible side effects of treatment(s) explained in a way you could understand?	338 (65.5%)	136 (26.4%)	30 (5.8%)	2 (0.4%)	10 (1.9%)
	Yes, and it was easy to understand	**Yes, and it was difficult to understand**	**No**	**I don't know/ can't remember**	
Before you started your treatment, were you given written information about the side effects of treatment(s)?	354 (69.4%)	54 (10.6%)	73 (14.3%)	29 (5.7%)	

^valid percentage, calculated based on non-missing data ---- = coded as yes, ---- = coded as no, no border = treated as missing

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5,6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7-13
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	7-13
Bias	9	Describe any efforts to address potential sources of bias	13 & 23
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	13
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	13
		(*b*) Describe any methods used to examine subgroups and interactions	13
		(*c*) Explain how missing data were addressed	14
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	-
		(*e*) Describe any sensitivity analyses	-
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7 (figure)
		(b) Give reasons for non-participation at each stage	7 (figure)
		(c) Consider use of a flow diagram	7 (figure)
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	14
		(b) Indicate number of participants with missing data for each variable of interest	15 – 16 (tables)
Outcome data	15*	Report numbers of outcome events or summary measures	15 – 16 (tables)
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	-
		(*b*) Report category boundaries when continuous variables were categorized	15-16
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	18-20
Discussion			
Key results	18	Summarise key results with reference to study objectives	21
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	22
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	21,22
Generalisability	21	Discuss the generalisability (external validity) of the study results	22
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	2

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Applying National Cancer Control Indicators to Regional and Remote Cancer Patients' Experiences

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Declarations

Conflict of interest

The authors declare that they have no conflict of interest.

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Ethical Approval

The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of Southern Queensland (Ethics approval number: ref. H17REA152).

Consent to participate

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

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author Contribution Statement

JD, BG, JFA, SM, FCW, MJI, NR, LZ, AR, & SKC contributed to the study conception and design. Material preparation and data collection were conducted by BG, FCW, AR, & LZ and analyses were performed by BG and MI. The first draft of the manuscript was written by JD and SKC and JD, BG, JFA, SM, FCW, MJI, NR, LZ, AR, & SKC provided substantial contributions in revising the manuscript and approved the final manuscript.

ABSTRACT

Objectives: To examine the health services experience of cancer patients from regional and remote Australia using the Australian National Cancer Control Indicators (NCCI) guidelines as an assessment framework.

Design: Cross-sectional.

Setting: Queensland non-for-profit cancer accommodation lodges.

Participants: Participants were cancer patients who travelled for treatment from rural and remote Queensland to major urban centres (n=518; age $M = 64.6$, SD =11.18).

Outcome measures: Assessments included NCCI patient indicators, quality of life (QoL), psychological distress and unmet supportive care needs.

Results: The frequency at which NCCI indicators were met ranged from 37.5% for receiving an assessment and care plan to 97.3% for understanding explanations about diagnosis. Middle school educated participants were more likely than those with senior level education or higher to receive an assessment and care plan (OR = 1.90, CI = 1.23 – 2.91) and to report having their views on treatment taken into account (OR = 2.22, CI = 1.49 – 3.33). Patients with breast or prostate cancer reported better communication and patient involvement and information and services provision (r = p <.001) compared to those with skin and head and neck cancer. When compared to information and service provision, communication and patient involvement showed stronger positive associations with QoL ($z = 2.03$, $p = .042$), psychosocial ($z = 2.05$, $p = .040$), and patient care ($z = 2.00$, $p = .046$) outcomes.

Conclusion: The patient care experience varies across the NCCI indicators by sociodemographic and clinical factors that likely reflects health care system biases. Perceptions about communication and involvement appear most critical for optimal outcomes and should be a priority action area for cancer control.

Keywords: cancer; health service; information; communication; patient experiences; cancer control.

Strengths and limitations of this study

- This large representative sample was recruited from a state-wide jurisdiction and so likely represents the actual experience of patients from regional and remote Australia.
- This study was cross-sectional therefore causality cannot be assumed.
- This study was aimed at gaining an insight into the experiences of regional and remote cancer patients, hence findings are not generalisable to urbanised populations.

INTRODUCTION

In Australia, as in other high income countries, cancer care delivery systems continue to be tested by increasing cancer prevalence due to an aging population and increasing survival. (1) Compounding this, widening socioeconomic and geographic inequities in cancer outcomes, (2) increasing healthcare costs, and workforce shortages (3,4) are all exacerbated by rapidly expanding, and complex, cancer diagnostic and treatment options. (5) In response, national societies and cancer control agencies globally have developed frameworks and guidelines for quality care cancer services that typically include characteristics such as being person-centered and tailored, evidence-based, coordinated, multi-disciplinary, quality assured and accountable. (6–9) While many of these guidelines focus on treatment, supportive and psychosocial care is also a central feature. For example, the first (of eight) recommendations from the Institute of Medicine 2013 report centers on patients and families receiving understandable information about all aspects of their cancer care. (8) The Australian Government's guides to best-practice cancer care, the Optimal Cancer Care Pathways, list access to supportive care, including survivorship, as a key theme across all steps of the care pathway. (7) Similarly, risk stratified pathways of cancer care in the UK emphasize assessing and supporting holistic patient needs, including those that are psychosocial and spiritual. While such frameworks are important, the question arises as to how cancer services might best evaluate the extent to which cancer care is meeting these recommendations, where gaps most exist, and crucially who is more vulnerable to underservicing.

A number of groups have developed indicators to reflect the extent to which optimal care is being delivered in terms of information, communication, education and care-coordination during diagnosis and treatment. (10,11) Thus far this been for quality assurance purposes within administering jurisdictions with findings not generally presented within the peer-reviewed literature. A set of items was recently developed by Cancer Australia for

monitoring cancer patient experiences at the national level. The National Cancer Control Indicators (NCCI) patient experiences items are based on the National Health Service (NHS) England Cancer Patient Experience Survey, (12) and reflect the receipt and understanding of information about diagnosis and side effects of treatment as well as patient involvement in care and decision making, and the provision of care co-ordination tools and services. To date, results from the Australian NCCI indicators for patient experience have not been reported.

It is especially important to consider the quality of the patient experience for people who live in geographically remote locations. People with cancer living in remote locations incur the additional burden of having to travel long distances to attend specialist treatment facilities that are not available in sparsely populated and geographically remote areas of the country. (13) Cancer patients who live outside of major cities in Australia are known to experience poorer cancer outcomes (14,15) and report poor physical and mental health, (16,17) lower quality of life (QoL) (18,19) and unmet supportive care needs (18,20,21) compared to their urban counterparts.

Accordingly, the present study applied the NCCI guidelines as a framework to examine the health services experience of cancer patients and their families from regional and remote Australia experiencing geographic dislocation while obtaining cancer treatment. In doing so: 1) the construct validity of the NCCI guidelines was examined, 2) the extent to which these guidelines are currently being met was tested, 3) sociodemographic predictors of underservicing were explored, and 4) how psychosocial outcomes, unmet supportive care needs, satisfaction with health care were related to underservice were described.

METHOD

Patient and Public Involvement Statement

Patient and public involvement in the design and conduct of the study was sought from community members, research volunteers, and pilot study participants. Several community members including cancer survivors living in rural areas reviewed interview and

questionnaire items providing feedback on the clarity, formatting, and time to complete. The research volunteers tested and evaluated materials and protocols while patients provided written and verbal feedback to researchers regarding clarity, burden and relevance associated with completing study materials. Minor refinements to the study materials to were made to increase clarity and ease of delivery based on this feedback.

Participants

Participants (n = 518) were cancer patients from regional and remote Queensland staying at six Cancer Council Queensland (CCQ) lodges. CCQ is a not for profit organization offering a range of services to those affected by cancer, one of those being the accommodation lodges which aim to limit out of pocket expenses for patients. People who are diagnosed with cancer, who are required to travel for their treatment, may receive a referral to stay at one of the CCQ lodges from their healthcare team. Accommodation costs are determined in conjunction with the patient's eligibility for the Queensland government's Patient Travel Subsidy Scheme which is designed to assist in the cost of travel to the nearest specialist medical service that is more than 50km from the patients nearest hospital. Figure 1 depicts participant recruitment flow. Eligibility criteria were: 18 years or older, able to read and understand English, and staying at a CCQ lodge for cancer treatment. A total of 1405 of 1801 eligible CCQ lodge guests staying between September 11th, 2017 and 1st February, 2020 were provided with an invitation pack containing study details, consent forms and a questionnaire. Three hundred and ninety-six eligible guests were not approached as contact details were not provided or accurate.

Invitation packs were distributed upon arrival by lodge staff or, if this was not possible (e.g., after hours check-in) were sent via mail to their home address. Patients were contacted by phone one week after pack distribution, offered further details and invited to participate. Assessments included a self-administered questionnaire and face-to-face (or telephone) interview at baseline, followed by self-administered questionnaires at 3 months, 12 months and annually thereafter.

Of the eligible patients who received an invitation pack (n=1405), 635 (45.2%) consented to participate, 395 (28.1%) actively refused, and 375 (26.7%) did not return a consent form and could not be re-contacted. This report focusses on data collected at baseline for a sample of 518 consenting participants who completed both the questionnaire and interview component of the study. Based on the available names and addresses of non-respondents it could be estimated that responders and non-responders did not differ significantly according to gender, remoteness, or socio-economic status.

Materials and measures

Questionnaires assessed demographic and patient characteristics, patient experiences according to the NCCI, psychological distress and cognitive adjustment, satisfaction with healthcare, QoL, and supportive care needs. Structured interviews assessed diagnostic and treatment pathways. The study has approval from a recognized institutional Human Research Ethics Committee (ref. H17REA152).

Demographics and patient characteristics

Site of current cancer, gender, age, country of birth, highest level of education, and household income were reported by each participant. Participant's residential street address at baseline was geocoded and mapped to the 2011 SA2 boundaries using MapMarker® Australia Version 15.16.0.21 and MapInfo Pro® Version 15.0 and classified by Remoteness Area (22) and Socio-Economic Indexes for Areas (SEIFA). (23) Most recently diagnosed primary cancer site was obtained via self-report and verified against the population-based Queensland Cancer Register (QCR). Self-report data were relied upon where diagnosis could not be verified by the QCR (n=39), for example if the patient had non-melanoma skin cancer (which is not routinely notified to registries in Australia) or the patient's diagnosis had not yet been notified to the QCR.

National Cancer Control Indicators - patient experience

Eight items derived from the National Health Service (NHS) England Cancer Patient Experience Survey (10) were adapted by Cancer Australia (12) as measures of National Cancer Control Indicators (NCCI) of cancer patient experiences. The items captured four key elements including 1) Patient information, communication and education during diagnosis; 2) Patient information, communication and education during; 3) Patient co-ordination and integration of care, continuity and transition; 4) Respect for patient preference. Response scales for each item vary including 3 category (e.g., yes, no, I don't know/remember) and 4 category (e.g., yes, yes to some extent, no, I don't know/remember) response options. Responses to each NCCI item were collapsed into a yes/no binary response with those responding with "I don't know" or "I don't remember" coded as missing. Full item wording, response categories and method for collapsing responses is available in as supplementary material (Supplementary Table 1).

As the NCCI items have not been validated for use in research an exploratory factor analysis was conducted for the current sample. One to four-factor solutions were extracted sequentially using Mplus v.8 software. (24).The decision on the number of factors to retain was driven by 1) overall and comparative model fit (determined by χ^2 and $\Delta\chi^2$ and their corresponding p values), 2) balancing the trade-off between explanatory power and parsimony (determined by the Bayesian and the Akaike information criteria), and 3) an interpretable pattern of strong and non-cross-loading factor loadings.

For the one to three-factor solutions, overall model fit improved as a function of the number of factors extracted (see Table 1). However, the four-factor solution yielded a poorer fit than the three-factor solution according to both χ^2 and information criteria values and was not considered a candidate solution. The Bayesian information criterion shows that the three-factor solution exhibited poorer fit compared to the two-factor solution once model complexity was accounted for. Therefore, the two-factor solution represented the best trade-off of explanatory power and parsimony. Finally, the two-factor solution also yielded a simple structure in the pattern of item loadings. Each NCCI item loaded cleanly onto one of each of the two factors (see Table 2); the first reflecting effective communication and patient involvement the second reflecting the provision of information or services. A confirmatory factor analytic approach was used to calculate factor score variables for the communication and patient involvement and provision of information and services. Factor score variables were transformed so that scores ranged from 0 (low) to 1.68 (high) for the communication and patient involvement factor and 0 (low) to 1.84 (high) for the provision of information and services factor.

Table 1. Comparative fit statistics for one to four factor EFA solutions

	1-factor	2-factor	3-factor	4-factor
AIC	3848.70	3784.24	3775.34	3787.09
ΔAIC	-	64.46	8.89	-11.74
BIC	3916.70	3881.99	3898.59	3931.59
ΔBIC	-	34.71	-16.61	-32.99
χ^2 (*p*)	435.96 (< .001)	306.55 (.001)	207.71 (.776)	225.45 (.368)
$\Delta\chi^2$ (*p*)	-	84.76 (< .001)	40.37 (< .001)	($\Delta\chi^2$ is negative)

Table 2. Exploratory factor analysis item loadings for two-factor solution

Item	**Communication and patient involvement**	**Provision of information and services**
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	**0.884***	0.005
Were you involved as much as you wanted to be in decisions about your care and treatment?	**0.925***	-0.063
Were the possible side effects of treatment(s) explained in a way you could understand?	**0.507***	0.249*
When you were told you had cancer, did you understand the explanation of what was wrong with you?	**0.633***	0.059
Have you been offered a written assessment and care plan?	0.185	**0.579***
When you were told you had cancer, were you given written information about the type of cancer you had?	0.075	**0.579***
Before you started your treatment, were you given written information about the side effects of treatment(s)?	0.002	**0.719***
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	-0.001	**0.736***

Geomin Rotated Loadings (* significant at 5% level)

Psychological distress and adjustment

Stress, anxiety and depression were measured using the 21-item Depression, Anxiety, and Stress Scale (DASS-21) (25). The scale asks respondents to indicate the degree to which each statement applied to them over the past week on a four-point Likert scale ranging from 0 = *not at all* to 3 = *almost always*. Scores for each subscale were summed and multiplied by 2, with higher scores indicating more distress. (26) Reliability for the anxiety (α = .67), stress (α = .87) and depression (α = .90) subscales were adequate to excellent.

Psychological adjustment to a cancer diagnosis was assessed using the Constructed Meaning Scale **(**CMS). The 8 item CMS measures a patients' cognitive response to being diagnosed with a life-threatening illness (27) on a 4-point Likert scale ranging from 1 = *strongly disagree* to 4 = *strongly agree*. Scores on the CMS reflect ability to construct a positive outlook regarding the effect that cancer has or will have on their future, their relationships, and their sense of self. Internal consistency in the current study was good (α = .77).

Satisfaction with healthcare

Nine items were created by the researchers to assess patients' satisfaction with their health care in terms of the referral process, speed of diagnosis, speed of test results, the hospital where they were treated and the doctors and nurses, the emotional and physical support they receive in hospital and finally, and their medical care overall. Degree of satisfaction with each item was reported on a 5-point Likert scale ranging from 1 = *very dissatisfied* to 5 = *very satisfied*. Data and participant feedback from the pilot phase were examined to ensure items were clear and relevant and excellent internal consistency for the measure was evident (α = .92). Items were averaged to create a mean score.

Quality of life

Regional and remote cancer patients' experiences

Multidimensional QoL was measured using the 35-item Assessment of Quality of Life 8 Dimension instrument (AQoL-8D)(28). Participants responded on a 5-point Likert scale based on aspects of QoL during the past week. Responses are coded so that lower scores reflect poorer QoL on two psychometrically derived dimensions reflecting physical and psychological wellbeing. Internal reliability was evident for physical (α = .64) and psychological (α = .92) dimensions in the current study.

Supportive care needs

Unmet need was measured using the Supportive Care Needs Survey Short Form-34 (SCNS-SF34). (29) The scale assesses patient need for support across five domains including physical and daily living, psychological, health systems and information, patient care and support, and sexuality with a single item regarding financial needs. Responses were coded: 0 (*no need/not applicable/need satisfied*), 1 (*low need*), 2 (*moderate need*), or 3 (*high need*) and means calculated resulting in six continuous variables reflecting the degree of need in each domain. Subscales showed excellent internal reliability (physical and daily living needs α = .86; psychological needs α = .94; health system and information needs α = .95; patient care and support needs α = .88; sexuality needs α = .87).

Analysis

Data analyses were carried out in SPSS Version 26. (30) Frequencies and percentages were calculated for patient responses to each NCCI item. Demographics and area-level characteristic differences in the likelihood of reporting *yes* to a NCCI item were examined using chi-square statistics. A family-wise error rate adjustment was applied to constrain the chance of Type 1 errors to 5%. One-way analyses of variance (ANOVA) were used to identify group differences in NCCI factor scores. Pearson's point biserial correlations assessed whether age was associated with NCCI items and factors. Where group differences were significant, post-hoc contrasts were applied to compare each category against others.

Odds ratios (OR) and 95% confidence intervals (CI) were reported for contrasts involving NCCI items. Associations between factor scores and health/psychosocial variables were assessed using a series of correlations with coefficients graphed and compared using a Fisher's *z*-test. Missing data were excluded from analyses in a pairwise manner.

RESULTS

Sample characteristics

Participant ages ranged from 26 to 93 (M = 64.6 , SD = 11.18) and 47.3% of participants identified as female and 52.7% as male. Most participants were born in Australia (80.5%), with the remainder born in the UK (9.9%), New Zealand (4.7%), and other countries (4.9%). Most participants reported low income with 64.8% reporting a household income under $50,000 a year (i.e., the median yearly gross income in Australia). Most patients were not fully covered by private health insurance (81.5%) and the majority lived in inner (44.0%) or outer (42.5%) regional areas marked by high levels of socio-economic disadvantage (i.e., 66.5% were in the lowest socio-economic quintiles). The most common primary cancers were breast (19.3%), head and neck (14.3%), and skin (12.6%). – see Table 3. Referenced to population statistics (31), the current sample was representative of the non-metropolitan Queensland cancer population in terms of gender, age, and country of birth. However, patients with skin cancer were under-represented (24.5% in population) and patients with head and neck cancer were over-represented (5.8% in population). At the time of data collection, time since diagnosis for each participant ranged between and 33.7 years and 1 day (Median = 211 days), with 64% of participants diagnosed within the previous 12 months.

Table 3. Participant characteristics and responses to NCCI items with chi-square and ANOVA group comparisons.

		Communication and patient involvement					**Provision of information and services**				
	Total n (%)^	Views on treatment n (%)	Involved in decisions n (%)	Side effects explained n (%)	Understand Explanation n (%)	Factor Score M (SD)	Written info on type of cancer n (%)	Assessment and care plan n (%)	Clinical nurse support n (%)	Written info on side effects n (%)	Factor Scor M (SD)
Gender		$\chi^2 = 2.69$	$\chi^2 = 1.30$	$\chi^2 = 0.32$	$\chi^2 = 0.10$	$F = 2.15$	$\chi^2 = 7.88$*	$\chi^2 = 0.23$	$\chi^2 = 1.05$	$\chi^2 = 1.46$	$F = 2.92$
Female	**245 (52.7%)**	147 (63.4%)	149 (63.4%)	156 (65.5%)	234 (97.5%)	1.17 (0.43)	163 (70.3%)	73 (36.3%)	157 (71.7%)	199 (86.9%)	1.36 (0.46)
Male	**273 (47.3%)**	147 (56.1%)	165 (58.4%)	182 (67.9%)	263 (97.0%)	1.11 (0.43)	152 (58.2%)	86 (38.6%)	160 (66.4%)	209 (82.9%)	1.21 (0.48)
Education		$\chi^2 = 16.61$*	144 (68.2%)	$\chi^2 = 9.70$*	$\chi^2 = 0.84$	$F = 9.24$	$\chi^2 = 3.00$	$\chi^2 = 11.44$*	$\chi^2 = 6.39$	$\chi^2 = 2.65$	$F = 7.46$*
Middle school (yr 10)	**217 (42.3%)**	146 (70.2%)	41 (55.4%)	155 (73.1%)	205 (96.7%)	1.23 (0.42)	141 (68.1%)	85 (47.0%)	141 (75.8%)	176 (86.7%)	1.27 (0.48)
Senior school (yr 12)	**78 (15.1%)**	39 (53.4%)	117 (55.2%)	41 (53.9%)	76 (98.7%)	1.05 (0.42)	44 (57.9%)	17 (28.3%)	47 (64.4%)	55 (78.6%)	1.07 (0.47)
Trade/Tertiary	**218 (42.5%)**	107 (51.4%)	$\chi^2 = 0.06$	139 (65.3%)	211 (97.2%)	1.08 (0.42)	128 (62.4%)	57 (31.8%)	127 (64.8%)	172 (84.7%)	1.12 (0.46)
> median income		$\chi^2 = 0.03$	182 (59.7%)	$\chi^2 = 0.06$	$\chi^2 = 2.17$	$F = 0.09$	$\chi^2 = 0.24$	$\chi^2 = 0.44$	$\chi^2 = 1.46$	$\chi^2 = 1.66$	$F = 0.01$
Yes	**318 (65.3%)**	73 (57.5%)	144 (68.2%)	84 (67.2%)	126 (99.2%)	1.14 (0.40)	81 (65.3%)	37 (34.9%)	77 (66.4%)	103 (88.8%)	1.17 (0.47)
No	**169 (34.7%)**	172 (58.3%)	78 (60.9%)	204 (66.0%)	301 (96.8%)	1.13 (0.44)	189 (62.8%)	100 (38.6%)	200 (72.5%)	248 (83.8%)	1.17 (0.48)
Born in Australia		$\chi^2 = 0.01$	$\chi^2 = 0.15$	$\chi^2 = 0.59$	$\chi^2 = 1.62$	$F = 0.18$	$\chi^2 = 0.55$	$\chi^2 = 0.15$	$\chi^2 = 0.43$	$\chi^2 = 0.85$	$F = 0.02$
Yes	**413 (80.5%)**	233 (59.6%)	238 (60.3%)	261 (65.6%)	387 (96.8%)	1.32 (0.44)	246 (63.2%)	127 (38.0%)	248 (69.5%)	322 (85.4%)	1.17 (0.48)
No	**100 (19.5%)**	58 (59.8%)	63 (62.4%)	71 (69.6%)	104 (99.0%)	1.15 (0.42)	66 (67.3%)	30 (35.7%)	64 (66.0%)	80 (81.6%)	1.16 (0.45)
Full PHI cover		$\chi^2 = 0.86$	$\chi^2 = 0.44$	$\chi^2 = 0.10$	$\chi^2 = 0.96$	$F = 0.26$	$\chi^2 = 0.32$	$\chi^2 = 0.05$	$\chi^2 = 3.38$	$\chi^2 = 0.85$	$F = 0.01$
Yes	**91 (18.5%)**	55 (64.7%)	56 (64.4%)	57 (65.5%)	85 (98.8%)	1.16 (0.24)	55 (67.1%)	27 (36.0%)	48 (60.0%)	73 (88.0%)	1.17 (0.47)
No	**400 (81.5%)**	224 (59.3%)	233 (60.5%)	261 (67.3%)	380 (96.9%)	1.37 (0.44)	242 (63.7%)	120 (37.4%)	247 (70.6%)	308 (83.9%)	1.17 (0.48)
Cancer Site		$\chi^2 = 4.97$	$\chi^2 = 8.65$	$\chi^2 = 2.59$	$\chi^2 = 1.37$	$F = 2.29$*	$\chi^2 = 29.65$*	$\chi^2 = 2.81$	$\chi^2 = 46.11$*	$\chi^2 = 17.43$*	$F = 8.03$*
Breast	**100 (19.3%)**	65 (68.4%)	66 (68.0%)	60 (61.9%)	97 (98.0%)	1.23 (0.43)	78 (80.4%)	33 (41.3%)	87 (92.6%)	84 (92.3%)	1.36 (0.39)
Skin	**65 (12.6%)**	38 (59.4%)	32 (50.8%)	39 (61.9%)	62 (95.4%)	1.05 (0.46)	29 (44.6%)	19 (34.5%)	27 (48.2%)	43 (69.4%)	0.97 (0.54)
Head & Neck	**74 (14.3%)**	39 (54.2%)	48 (66.7%)	51 (68.9%)	71 (97.3%)	1.14 (0.42)	37 (52.9%)	26 (44.8%)	39 (66.1%)	60 (85.7%)	1.16 (0.48)
Prostate	**64 (12.3%)**	38 (62.3%)	43 (67.2%)	43 (68.3%)	62 (98.4%)	1.20 (0.41)	47 (75.8%)	20 (37.7%)	47 (81.0%)	49 (80.3%)	1.25 (0.45)
Other	**215 (41.5%)**	114 (56.4%)	116 (56.3%)	145 (69.4%)	205 (97.2%)	1.10 (0.24)	124 (62.3%)	61 (34.3%)	117 (60.6%)	172 (87.3%	1.12 (0.46)
TOTAL	**518 (100%)**	294 (59.5%)	305 (60.8%)	338 (66.8%)	498 (97.3%)	1.14 (0.43)	316 (64.0%)	159 (37.5%)	317 (68.9%)	408 (84.8%)	1.17 (0.47)

PHI – Private Health Insurance. n (%) = number and percentage of participants in each demographic category responding yes to item, M (SD) = Mean and SD reported for factor scores, ^ valid percent calculated based on non-missing responses to this item, *= $p < .05$ (applying family-wise error rate adjustment for multiple χ^2 tests)

Table 3 cont. Participant characteristic and responses to NCCI items with chi-square and ANOVA group comparisons.

		Communication and patient involvement					**Provision of information and services**				
	Total n (%)	Views on treatment n (%)	Involved in decisions n (%)	Side effects explained n (%)	Understand explanation n (%)	Factor Score M (SD)	Written info on type of cancer n (%)	Assessment and care plan n (%)	Clinical nurse support n (%)	Written info on side effects n (%)	Factor Score M (SD)
SEIFA Quintile		$\chi^2 = 5.29$	$\chi^2 = 3.45$	$\chi^2 = 4.04$	$\chi^2 = 4.59$	$F = 0.61$	$\chi^2 = 1.30$	$\chi^2 = 0.90$	$\chi^2 = 5.58$	$\chi^2 = 2.64$	$F = 0.41$
1st (lowest)	**185 (36.0%)**	115 (64.2%)	110 (60.8%)	129 (71.3%)	180 (98.4%)	1.17 (0.43)	113 (63.8%)	56 (37.3%)	118 (71.1%)	154 (88.0%)	1.20 (0.46)
2nd	**155 (30.3%)**	89 (60.5%)	93 (61.2%)	99 (65.6%)	147 (96.1%)	1.12 (0.45)	98 (65.8%)	49 (38.9%)	90 (65.7%)	122 (82.4%)	1.16 (0.49)
3rd	**112 (21.9%)**	59 (57.3%)	59 (56.75)	65 (60.2%)	105 (95.5%)	1.09 (0.44)	66 (63.5%)	36 (40.9%)	71 (72.4%)	82 (83.7%)	1.17 (0.49)
4th	**54 (10.6%)**	25 (47.2%)	37 (69.8%)	37 (68.5%)	54 (100.0%)	1.12 (0.39)	32 (59.3%)	17 (34.7%)	31 (64.6%)	42 (82.4%)	1.13 (0.48)
5th (highest)	**5 (1.0%)**	3 (60.0%)	2 (40.0%)	3 (60.0%)	5 (100.0%)	1.04 (0.43)	4 (80.0%)	1 (25.0%)	1 (25.0%)	3 (75.0%)	1.02 (0.041)
ARIA		$\chi^2 = 5.22$	$\chi^2 = 3.35$	$\chi^2 = 4.55$	$\chi^2 = 2.66$	$F = 0.48$	$\chi^2 = 0.99$	$\chi^2 = 4.67$	$\chi^2 = 2.47$	$\chi^2 = 0.94$	$F = 0.99$
Major city	**24 (4.7%)**	9 (37.5%)	14 (58.3%)	13 (54.2%)	24 (100.0%)	1.03 (0.44)	17 (70.8%)	10 (41.7%)	14 (63.6%)	20 (90.9%)	1.17 (0.46)
Inner regional	**225 (44.0%)**	128 (60.7%)	140 (63.6%)	154 (70.3%)	216 (97.3%)	1.15 (0.38)	139 (64.7%)	61 (33.5%)	133 (68.6%)	177 (83.5%)	1.16 (0.44)
Outer regional	**217 (42.5%)**	128 (61.0%)	125 (60.4%)	140 (65.7%)	207 (96.3%)	1.12 (0.47)	129 (62.3%)	76 (43.4%)	134 (68.0%)	172 (85.1%)	1.19 (0.52)
Remote	**23 (4.5%)**	13 (61.9%)	12 (54.5%)	14 (66.7%)	23 (100.0%)	1.14 (0.44)	13 (61.9%)	7 (38.9%)	14 (66.7%)	16 (84.2%)	1.17 (0.50)
Very remote	**22 (4.3%)**	13 (61.9%)	10 (45.5%)	12 (54.5%)	21 (100.0%)	1.08 (0.43)	15 (68.2%)	5 (27.8%)	16 (84.2%)	18 (85.7%)	1.18 (0.48)

n(%) = number and percentage of participants in each area-level category responding yes to item, M (SD) = Mean and SD reported for factor scores,
*= $p < .05$ (applying family-wise error rate adjustment)

Communication and patient involvement

Participants reported that their views were taken into account when their team of doctors and nurses were discussing their treatment 59.5% of the time (Table 3). Those with middle school education or lower were twice as likely to report having their views taken into account in treatment decisions (OR = 2.22, CI = 1.49 – 3.33) compared to those with senior high school or trade/tertiary level education. Older patients were slightly more likely to report that their views were taken into account by doctors and nurses when deciding on treatment ($r = .11$, $p = .02$). Similarly, 60.8% of participants felt they were involved in decisions about their care and treatment as much as they would have liked, however, this did not vary according to individual characteristics.

Most participants reported understanding the explanation of "what was wrong with them" upon diagnosis (97.3%) and this did not differ significantly according to individual characteristics. More than half of the patients (66.8%) reported that the possible side-effects of their treatment were explained to them in a way they could understand. Those with middle school education or lower were 1.5 times more likely to report having side effects explained to them in a way that they understood compared to those with trade/tertiary level education (OR = 1.50, CI = 1.14 – 1.96) and those with senior level education were less likely to report this compared to those with trade/tertiary level education (OR = 0.65, CI = 0.46 – 0.90).

Group differences were evident in participants' scores on the communication and patient involvement factor with patients possessing middle school level education (M = 1.23, SD = 0.42) reporting higher scores than those with trade/tertiary level education (M = 1.08, SD = 0.42), t (509) = 42.75, $p < .001$, $d = 0.36$, or those with senior school level education (M = 1.05, SD = 0.42), t (509) = 21.88, $p < .001$, $d = 0.43$. When compared with all other cancer types, patients with breast (M = 1.23, SD = 0.43), t (512) = 28.75, $p < .001$, $d = 0.28$, and prostate (M = 1.20, SD = 0.41), t (512) = 22.40, $p < .001$, $d = 0.17$ cancer reported higher

scores on the communication and patient involvement factor, while those with skin (M = 1.05, SD = 0.46), t (512) = 19.75, *p* <.001, *d* = 0.22 and head and neck (M = 1.14, SD = 0.42), t (512) = 22.83, *p* <.001, *d* = 0.01 cancers reported lower scores than those with other cancer types.

Provision of information and services

Sixty-four percent of participants were given written information about the type of cancer they had. Females were 1.69 (CI = 1.16 – 2.46) times as likely to report receiving this information when compared to males. Patients with breast cancer were 2.41 (CI = 1.39 – 4.42) times more likely, and those with skin cancer were 0.49 (CI = 0.28 – 1.18) times as likely to receive written information about the type of cancer they had compared to those with other cancers. The majority of patients reported being given written information about the side effects of treatment (84.8%) with those with skin cancer less likely to receive this information compared to those with other cancer types 0.33 (CI= 0.17 – 0.65).

Only 37.5% of participants reported receiving a written assessment and care plan. Those with middle school education or lower were almost two times more likely to report receiving an assessment and care plan (OR = 1.90, CI = 1.23 – 2.91) compared to those with senior high school or trade/tertiary level education. Over two thirds of patients reported being given the name of a clinical nurse specialist to support them through treatment (68.9%), however, patients with breast cancer were 8.07 (CI = 3.55 – 18.37) times more likely, and patients with prostate cancer patients were 2.77 (CI = 1.36– 5.68) times more likely, to be offered this service compared to participants with other types of cancer.

Those with middle school level education or lower (M = 1.27, SD = 0.48) reported higher scores on the provision of service and information factor than those with trade/tertiary level education (M = 1.12, SD = 0.47), t (509) = 39.71, *p* <.001, *d* = 0.32 or those with senior school level education (M = 1.07, SD = 0.46), t (509)= 20.28, *p* <.001, *d* = 0.42. When compared with all other cancer types, patients with breast (M = 1.36, SD = 0.39), t (99) =

34.47, *p* <.001, *d* = 0.54 or prostate (M = 1.25, SD = 0.45), t (63) = 22.42, *p* <.001, *d* = 0.19 cancer reported higher scores on the provision of information and services factor, while those with skin (M = 0.97, SD = 0.54), t (64) = 14.52, *p* = <.001, *d* = 0.46 or head and neck (M = 1.16, SD = 0.48), t (73) = 20.73, *p* <.001, *d* = 0.03 cancers reported lower scores than those with other cancer types. Area-level characteristics (i.e., remoteness or SEIFA) were not significantly associated with single items or factor scores reflecting provision of information and services (see Table 3).

Associations between NCCI factor scores and health and psychosocial variables

Both communication and patient involvement and provision of information and services factors shared significant positive associations with QoL, satisfaction with health care and constructed meaning (see Figure 2). They were also both associated with lower supportive care needs in most cases, the strongest associations being with health system and information needs. The communication and patient involvement factor was moderately associated with greater psychosocial QoL (*r* = .30, *p* <.001) and satisfaction with healthcare (*r* = .29, *p* <.001) as well as lower levels of unmet 'health systems and information' (*r* = -.39, *p* <.001). and 'patient care' (*r* = .35, *p* <.001) needs and lower cancer threat appraisal (*r* = .31, *p* <.001). The provision of information and services factor had a weaker pattern of associations though still moderately predicted lower levels of unmet 'health systems and information' (*r* = -.32, *p* <.001) and 'patient care' (*r* = -.23, *p* <.001) needs as well as greater satisfaction with healthcare (*r* = .23, *p* <.001). The communication and patient involvement factor shared significantly stronger associations with higher psychosocial QoL (*z* = 2.03, *p* = .042), and lower levels of unmet need in terms of psychosocial support (*z* = 2.05, *p* =.040) and patient care (*z* = 2.00, *p* =.046). Communication and patient involvement was associated with lower stress and anxiety, while provision of information and services was not (see Figure 2).

Regional and remote cancer patients' experiences

Area-level characteristics (i.e., remoteness or SEIFA) were not significantly associated with single items or scores on either NCCI factor (see Table 3).

DISCUSSION

The goal of delivering equitable patient-centered cancer care is a corner stone of cancer control plans and care guidelines. (6,7,9,12) The present study suggests that the NCCI patient experience indicators have validity and strong potential as a quality assurance tool to support this. Importantly, this brief tool discriminated between different aspects of patient experience for those dislocated from their home during treatment and identified characteristics associated with a poorer experience. While it was almost universal for patients to recall understanding the explanation of their treatment, and most people reported that treatment side effects were explained and supported with written information, only a minority received a written assessment and care plan. Further, patient experience varied by clinical and sociodemographic characteristics suggesting that there is work to be done on better understanding what influences care, and how we might intervene.

From a construct perspective, the patient experience as measured by the NCCI indicators presented along two key dimensions: 1) communication and patient involvement and 2) provision of information and services. For both dimensions, the strong association with health system and information needs provides evidence of convergent validity. The closer connection between communication and patient involvement and QoL and psychosocial outcomes intuitively makes sense given the important role of the interpersonal relationships between the health care teams and patients, as well as the self-efficacy and personal agency that evolves from patient's involvement in their health care. (32) These associations may be bi-directional. Patients with lower psychological distress have a higher capacity to absorb information, take part in decision making, benefit from communications with healthcare professionals (33,34) and are subsequently more likely to report satisfaction with this element of their care. (35) Those individuals who are psychologically vulnerable or have poorer QoL likely need stepped up care to achieve optimal outcomes. (36)

Despite suggestions than remote living is associated with poorer experiences for cancer survivors, area level factors were not associated with NCCI outcomes. Rather, differences in patient experiences according to cancer were apparent. Notably, breast and prostate cancer patients were more likely to receive clinical nurse support compared to skin and head and neck cancer patients. This may reflect the different resources and services available for specific cancers, for example, the introduction of the specialist nurse role for breast cancer patients, (37) and more recently prostate cancer patients. (38) While a specialist nurse appears to greatly enhance patient experience, (39) providing this for all cancer types is likely a resourcing challenge especially for regional and remote health services. Models that incorporate telehealth and that span broadly across multiple cancer types or chronic disease may be needed. (40) Higher education appeared to be associated with less communication and patient involvement and information and services. The reasons for this are unclear however it may be that health professionals assume these patients require less support or alternatively that people with more education have greater expectations in this domain of care.

As the aim of the present study was to provide specific insight into the experiences of regional and remote cancer patients, caution should be in applied in generalising these findings to urbanised populations. Since the survey is cross-sectional we cannot assume causality; and the data is self-reported and was not able to be verified by observational data or care records. However, this large, representative sample was recruited from a statewide jurisdiction and so likely represents the actual experience of patients from regional and remote Australia. Although the aim of the current research was to assess patient experiences using a metric published by a National governing body, it is important to note that several valid measures of patient experience covering different aspects of patients' care and support needs exist and future research will benefit from their inclusion.

The present results outline the patient experience for a rural and regional population who are at risk of fragmented or poorly coordinated care. Patients who report better communication with their health care team and more involvement have better QoL, less stress and anxiety, and lower threat. Fulfilling the NCCI indicators connects to lower unmet need in health services and information. Cancer care services that ensure these indicators are met are better placed to provide an optimal cancer experience and improved patient-reported outcomes.

The NCCI presents as a useful and valid tool for assessing the patient experience. The aspect of care that appears most crucial is communication and involvement with the health care team. Strategies to optimize this for regional and remote patients need to be a cancer control priority.

Figure Captions:

Figure 1. Recruitment flowchart

Figure 2. Visual comparison of the correlation co-efficients between each health/psychosocial variable and each factor.

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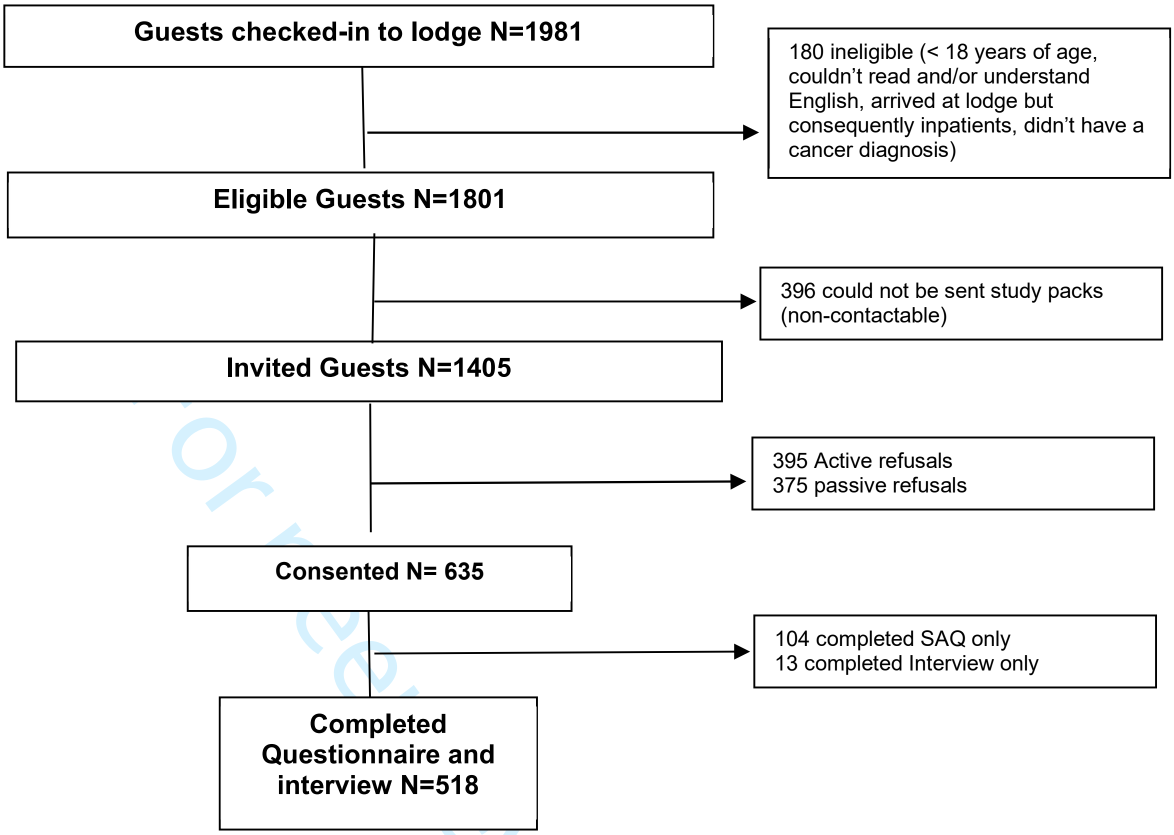
Figure 1. Recruitment flowchart



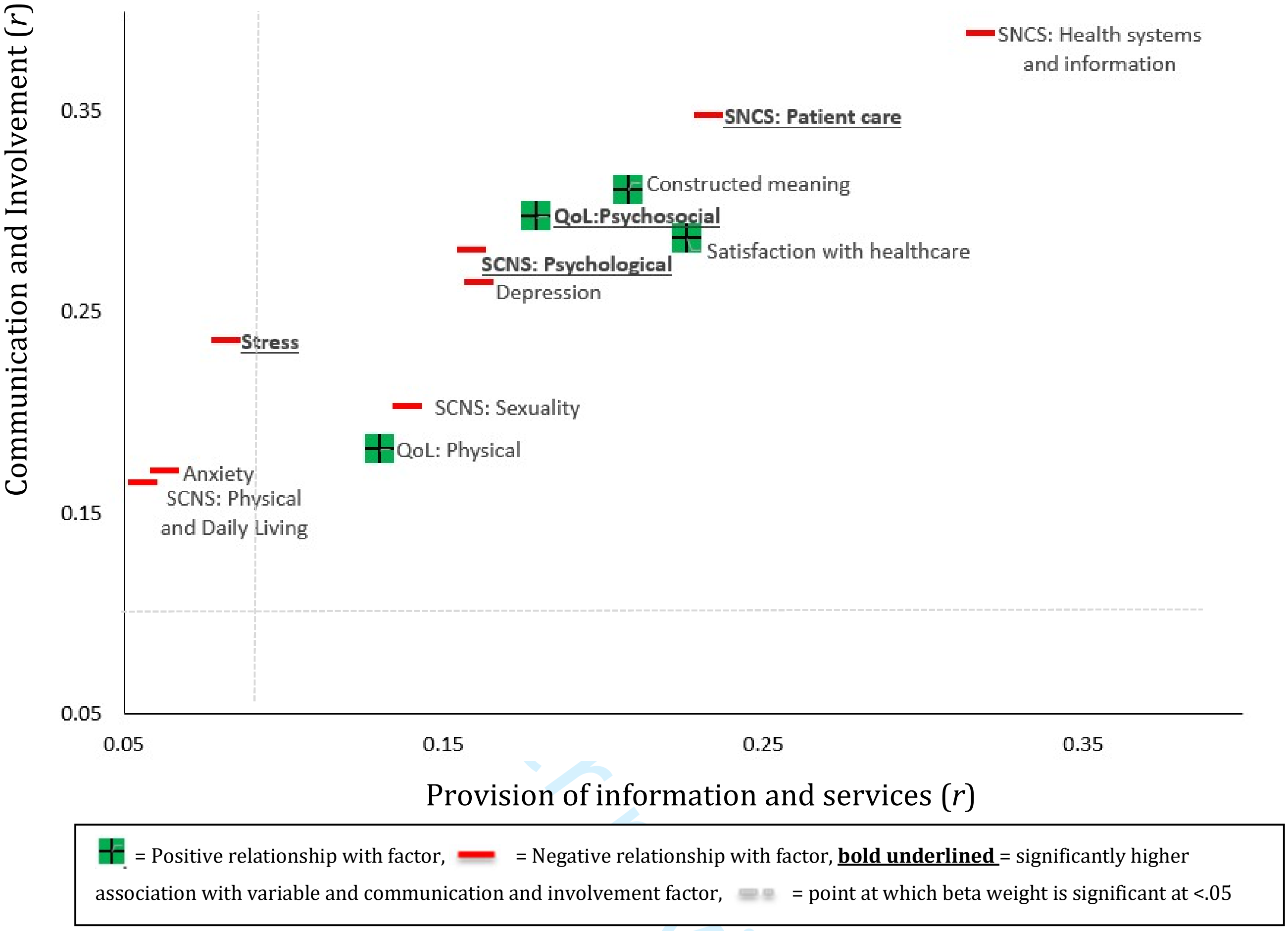


Figure 2. Visual comparison of the correlation co-efficients between each health/psychosocial variable and each factor.

Applying National Cancer Control Indicators to Regional and Remote Cancer Patients' Experiences Jeff Dunn, Belinda C Goodwin (belindagoodwin@cancerqld.org.au), Joanne F. Aitken, Sonja March, Fiona Crawford-Williams, Michael J. Ireland, Nicholas Ralph, Leah Zajdlewicz, Arlen Rowe, and Suzanne K. Chambers.
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Supplementary Table 1. Frequencies and percentages^ of responses to NCCI – Patient Experience Items and grouping of binary responses, n (%).

	Yes, I completely understood it	**Yes, I understood some of it**	**No**	**I can't remember**		**Missing**
When you were told you had cancer, did you understand the explanation of what was wrong with you?	345 (66.7%)	153 (29.4%)	14 (2.7%)	5 (1.0%)		1 (0.19%)
	Yes, and it was easy to understand	**Yes, and it was difficult to understand**	**No**	**I did not need written information**	**I don't know/ can't remember**	**Missing**
When you were told you had cancer, were you given written information about the type of cancer you had?	262 (51.3%)	54 (10.6%)	134 (26.2%)	44 (8.6%)	17 (3/3%)	7 (1.4%)
	Yes	**No**	**I don't know/ can't remember**			**Missing**
Have you been offered a written assessment and care plan	159 (31.0%)	265 (51.7%)	89 (17.3%)			5 (1.0%)
	Yes	**No**	**I don't know/ can't remember**			**Missing**
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	317 (61.8%)	143 (27.9%)	53 (10.2%)			5 (1.0%)
	Yes, definitely	**Yes, to some extent**	**No, but I would have liked to be more involved**	**I don't know/can't remember**		**Missing**
Were you involved as much as you wanted to be in decisions about your care and treatment?	305 (59.2%)	161 (31.3%)	36 (6.9%)	13 (2.5%)		3 (0.6%)

^valid percentage reported except for missing column, calculated based on non-missing data ---- = coded as yes, ---- = coded as no, no border = treated as missing

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Supplementary Table 1. (Cont.)

	Yes, definitely	**Yes, to some extent**	**No**	**I didn't know my treatment was being discussed …**	**I don't know/ can't remember**	**Missing**
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	294 (57.8%)	152 (29.2%)	31 (6.1%)	17 (2.9%)	15 (2.8%)	9 (1.7%)
	Yes, definitely	**Yes, to some extent**	**No**	**I did not need an explanation**	**I don't know/ can't remember**	**Missing**
Were the possible side effects of treatment(s) explained in a way you could understand?	338 (65.5%)	136 (26.4%)	30 (5.8%)	2 (0.4%)	10 (1.9%)	2 (0.4%)
	Yes, and it was easy to understand	**Yes, and it was difficult to understand**	**No**	**I don't know/ can't remember**		**Missing**
Before you started your treatment, were you given written information about the side effects of treatment(s)?	354 (69.4%)	54 (10.6%)	73 (14.3%)	29 (5.7%)		8 (1.5%)

^valid percentage reported except for missing column, calculated based on non-missing data - - - - = coded as yes, - - - - = coded as no, no border = treated as missing

Note: To assess whether time since diagnosis was associated with non-response (i.e., no response or I don't know/ don't remember response), point bi-serial correlations were conducted between non-response and days since diagnosis. One weak association whereby those who were further past diagnosis were less likely to recall/provide a response to the NCCI item "Were you involved as much as you wanted to be in decisions about your care and treatment" (*r* = .130, *p* =.004)

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	**Item #**	**Recommendation**	**Reported on page #**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5,6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7-13
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	7-13
Bias	9	Describe any efforts to address potential sources of bias	13 & 23
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	13
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	13
		(*b*) Describe any methods used to examine subgroups and interactions	13
		(*c*) Explain how missing data were addressed	14
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	-
		(*e*) Describe any sensitivity analyses	-
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7 (figure)
		(b) Give reasons for non-participation at each stage	7 (figure)
		(c) Consider use of a flow diagram	7 (figure)
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	14
		(b) Indicate number of participants with missing data for each variable of interest	15 – 16 (tables)
Outcome data	15*	Report numbers of outcome events or summary measures	15 – 16 (tables)
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	-
		(*b*) Report category boundaries when continuous variables were categorized	15-16
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	18-20
Discussion			
Key results	18	Summarise key results with reference to study objectives	21
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	22
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	21,22
Generalisability	21	Discuss the generalisability (external validity) of the study results	22
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	2

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Are National Cancer Control Indicators for Patient Experiences being met in Regional and Remote Australia? A cross-sectional study of Cancer Survivors who Travelled for Treatment.

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Are National Cancer Control Indicators for Patient Experiences being met in Regional and Remote Australia? A cross-sectional study of Cancer Survivors who Travelled for Treatment.

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ABSTRACT

Objectives: To examine the health services experience of cancer patients from regional and remote Australia using the Australian National Cancer Control Indicators (NCCI) guidelines as an assessment framework.

Design: Cross-sectional.

Setting: Queensland non-for-profit cancer accommodation lodges.

Participants: Participants were cancer patients who travelled for treatment from rural and remote Queensland to major urban centres (n=518; age $M = 64.6$, SD =11.18).

Outcome measures: Assessments included NCCI patient indicators, quality of life (QoL), psychological distress and unmet supportive care needs.

Results: The frequency at which NCCI indicators were met ranged from 37.5% for receiving an assessment and care plan to 97.3% for understanding explanations about diagnosis. Geographical considerations did not impact patient experience whereas middle school educated participants were more likely than those with senior level education or higher to receive an assessment and care plan (OR = 1.90, CI = 1.23 – 2.91) and to report having their views on treatment taken into account (OR = 2.22, CI = 1.49 – 3.33). Patients with breast or prostate cancer reported better communication and patient involvement and information and services provision ($r = p < .001$) compared to those with skin and head and neck cancer. When compared to information and service provision, communication and patient involvement showed stronger positive associations with QoL ($z = 2.03$, $p = .042$), psychosocial ($z = 2.05$, $p = .040$), and patient care ($z = 2.00$, $p = .046$) outcomes.

Conclusion: The patient care experience varies across the NCCI indicators by sociodemographic and clinical factors that likely reflects health care system biases. Perceptions about communication and involvement appear most critical for optimal outcomes and should be a priority action area for cancer control.

Keywords: cancer; health service; information; communication; patient experiences; cancer control.

Strengths and limitations of this study

- This is the first study to quantitatively measure and test the National Cancer Control Indicators for patient experience.
- Findings provide important insight into the patient experience for a regional and remote population who are at risk of fragmented or poorly coordinated care.
- This large representative sample was recruited from a state-wide jurisdiction and so likely represents the actual experience of patients from regional and remote Australia.
- This study was cross-sectional therefore causality cannot be assumed.
- This study was aimed at gaining an insight into the experiences of regional and remote cancer patients, hence findings are not generalisable to urbanised populations.

INTRODUCTION

In Australia, as in other high income countries, cancer care delivery systems continue to be tested by increasing cancer prevalence due to an aging population and increasing survival. (1) Compounding this, widening socioeconomic and geographic inequities in cancer outcomes, (2) increasing healthcare costs, and workforce shortages (3,4) are all exacerbated by rapidly expanding, and complex, cancer diagnostic and treatment options. (5) In response, national societies and cancer control agencies globally have developed frameworks and guidelines for quality care cancer services that typically include characteristics such as being person-centered and tailored, evidence-based, coordinated, multi-disciplinary, quality assured and accountable. (6–9) While many of these guidelines focus on treatment, supportive and psychosocial care is also a central feature. For example, the first (of eight) recommendations from the Institute of Medicine 2013 report centers on patients and families receiving understandable information about all aspects of their cancer care. (8) The Australian Government's guides to best-practice cancer care, the Optimal Cancer Care Pathways, list access to supportive care, including survivorship, as a key theme across all steps of the care pathway. (7) Similarly, risk stratified pathways of cancer care in the UK emphasize assessing and supporting holistic patient needs, including those that are psychosocial and spiritual. While such frameworks are important, the question arises as to how cancer services might best evaluate the extent to which cancer care is meeting these recommendations, where gaps most exist, and crucially who is more vulnerable to underservicing.

A number of groups have developed indicators to reflect the extent to which optimal care is being delivered in terms of information, communication, education and care-coordination during diagnosis and treatment. (10,11) Thus far this been for quality assurance purposes within administering jurisdictions with findings not generally presented within the peer-reviewed literature. A set of items was recently developed by Cancer Australia for

monitoring cancer patient experiences at the national level. The National Cancer Control Indicators (NCCI) patient experiences items are based on the National Health Service (NHS) England Cancer Patient Experience Survey, (12) and reflect the receipt and understanding of information about diagnosis and side effects of treatment as well as patient involvement in care and decision making, and the provision of care co-ordination tools and services. To date, results from the Australian NCCI indicators for patient experience have not been reported.

It is especially important to consider the quality of the patient experience for people who live in geographically remote locations. People with cancer living in remote locations incur the additional burden of having to travel long distances to attend specialist treatment facilities that are not available in sparsely populated and geographically remote areas of the country. (13) Cancer patients who live outside of major cities in Australia are known to experience poorer cancer outcomes (14,15) and report poor physical and mental health, (16,17) lower quality of life (QoL) (18,19) and unmet supportive care needs (18,20,21) compared to their urban counterparts.

Accordingly, the present study applied the NCCI guidelines as a framework to examine the health services experience of cancer patients and their families from regional and remote Australia experiencing geographic dislocation while obtaining cancer treatment. In doing so: 1) the construct validity of the NCCI guidelines was examined, 2) the extent to which these guidelines are currently being met was tested, 3) sociodemographic predictors of underservicing were explored, and 4) how psychosocial outcomes, unmet supportive care needs, satisfaction with health care were related to underservice were described.

METHOD

Patient and Public Involvement Statement

Patient and public involvement in the design and conduct of the study was sought from community members, research volunteers, and pilot study participants. Several community members including cancer survivors living in rural areas reviewed interview and

questionnaire items providing feedback on the clarity, formatting, and time to complete. The research volunteers tested and evaluated materials and protocols while patients provided written and verbal feedback to researchers regarding clarity, burden and relevance associated with completing study materials. Minor refinements to the study materials to were made to increase clarity and ease of delivery based on this feedback.

Participants

Participants (n = 518) were cancer patients from regional and remote Queensland staying at six Cancer Council Queensland (CCQ) lodges. CCQ is a not for profit organization offering a range of services to those affected by cancer, one of those being the accommodation lodges which aim to limit out of pocket expenses for patients. People who are diagnosed with cancer, who are required to travel for their treatment, may receive a referral to stay at one of the CCQ lodges from their healthcare team. Accommodation costs are determined in conjunction with the patient's eligibility for the Queensland government's Patient Travel Subsidy Scheme which is designed to assist in the cost of travel to the nearest specialist medical service that is more than 50km from the patients nearest hospital. Figure 1 depicts participant recruitment flow. Eligibility criteria were: 18 years or older, able to read and understand English, and staying at a CCQ lodge for cancer treatment. A total of 14015 of 1811 eligible CCQ lodge guests staying between September 11th, 2017 and 1st February, 2020 were provided with an invitation pack containing study details, consent forms and a questionnaire. Three hundred and ninety-six eligible guests were not approached as contact details were not provided or accurate.

Invitation packs were distributed upon arrival by lodge staff or, if this was not possible (e.g., after hours check-in) were sent via mail to their home address. Patients were contacted by phone one week after pack distribution, offered further details and invited to participate. Assessments included a self-administered questionnaire and face-to-face (or telephone) interview at baseline, followed by self-administered questionnaires at 3 months, 12 months and annually thereafter.

Of the eligible patients who received an invitation pack (n=1415), 645 (45.2%) consented to participate, 395 (28.1%) actively refused, and 375 (26.7%) did not return a consent form and could not be re-contacted. This report focusses on data collected at baseline for a sample of 518 consenting participants who had a cancer diagnosis and completed both the questionnaire and interview component of the study. Based on the available names and addresses of non-respondents it could be estimated that responders and non-responders did not differ significantly according to gender, remoteness, or socio-economic status.

Materials and measures

Questionnaires assessed demographic and patient characteristics, patient experiences according to the NCCI, psychological distress and cognitive adjustment, satisfaction with healthcare, QoL, and supportive care needs. Structured interviews assessed diagnostic and treatment pathways. The study has approval from a recognized institutional Human Research Ethics Committee (ref. H17REA152).

Demographics and patient characteristics

Site of current cancer, gender, age, country of birth, highest level of education, and household income were reported by each participant. Participant's residential street address at baseline was geocoded and mapped to the 2011 SA2 boundaries using MapMarker® Australia Version 15.16.0.21 and MapInfo Pro® Version 15.0 and classified by Remoteness Area (22) and Socio-Economic Indexes for Areas (SEIFA). (23) Most recently diagnosed primary cancer site was obtained via self-report and verified against the population-based Queensland Cancer Register (QCR). Self-report data were relied upon where diagnosis could not be verified by the QCR (n=39), for example if the patient had non-melanoma skin cancer (which is not routinely notified to registries in Australia) or the patient's diagnosis had not yet been notified to the QCR.

National Cancer Control Indicators - patient experience

Eight items derived from the National Health Service (NHS) England Cancer Patient Experience Survey (10) were adapted by Cancer Australia (12) as measures of National Cancer Control Indicators (NCCI) of cancer patient experiences. The items captured four key elements including 1) Patient information, communication and education during diagnosis; 2) Patient information, communication and education during; 3) Patient co-ordination and integration of care, continuity and transition; 4) Respect for patient preference. Response scales for each item vary including 3 category (e.g., yes, no, I don't know/remember) and 4 category (e.g., yes, yes to some extent, no, I don't know/remember) response options. Responses to each NCCI item were collapsed into a yes/no binary response with those responding with "I don't know" or "I don't remember" coded as missing. Full item wording, response categories and method for collapsing responses is available in as supplementary material (Supplementary Table 1).

As the NCCI items have not been validated for use in research an exploratory factor analysis was conducted for the current sample. One to four-factor solutions were extracted sequentially using Mplus v.8 software. (24).The decision on the number of factors to retain was driven by 1) overall and comparative model fit (determined by χ^2 and $\Delta\chi^2$ and their corresponding p values), 2) balancing the trade-off between explanatory power and parsimony (determined by the Bayesian and the Akaike information criteria), and 3) an interpretable pattern of strong and non-cross-loading factor loadings.

For the one to three-factor solutions, overall model fit improved as a function of the number of factors extracted (see Table 1). However, the four-factor solution yielded a poorer fit than the three-factor solution according to both χ^2 and information criteria values and was not considered a candidate solution. The Bayesian information criterion shows that the three-factor solution exhibited poorer fit compared to the two-factor solution once model complexity was accounted for. Therefore, the two-factor solution represented the best trade-off of explanatory power and parsimony. Finally, the two-factor solution also yielded a simple structure in the pattern of item loadings. Each NCCI item loaded cleanly onto one of each of the two factors (see Table 2); the first reflecting effective communication and patient involvement the second reflecting the provision of information or services. A confirmatory factor analytic approach was used to calculate factor score variables for the communication and patient involvement and provision of information and services. Factor score variables were transformed so that scores ranged from 0 (low) to 1.68 (high) for the communication and patient involvement factor and 0 (low) to 1.84 (high) for the provision of information and services factor.

Table 1. Comparative fit statistics for one to four factor EFA solutions

	1-factor	2-factor	3-factor	4-factor
AIC	3848.70	3784.24	3775.34	3787.09
ΔAIC	-	64.46	8.89	-11.74
BIC	3916.70	3881.99	3898.59	3931.59
ΔBIC	-	34.71	-16.61	-32.99
χ^2 (*p*)	435.96 (< .001)	306.55 (.001)	207.71 (.776)	225.45 (.368)
$\Delta\chi^2$ (*p*)	-	84.76 (< .001)	40.37 (< .001)	($\Delta\chi^2$ is negative)

Table 2. Exploratory factor analysis item loadings for two-factor solution

Item	**Communication and patient involvement**	**Provision of information and services**
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	**0.884***	0.005
Were you involved as much as you wanted to be in decisions about your care and treatment?	**0.925***	-0.063
Were the possible side effects of treatment(s) explained in a way you could understand?	**0.507***	0.249*
When you were told you had cancer, did you understand the explanation of what was wrong with you?	**0.633***	0.059
Have you been offered a written assessment and care plan?	0.185	**0.579***
When you were told you had cancer, were you given written information about the type of cancer you had?	0.075	**0.579***
Before you started your treatment, were you given written information about the side effects of treatment(s)?	0.002	**0.719***
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	-0.001	**0.736***

Geomin Rotated Loadings (* significant at 5% level)

Psychological distress and adjustment

Stress, anxiety and depression were measured using the 21-item Depression, Anxiety, and Stress Scale (DASS-21) (25). The scale asks respondents to indicate the degree to which each statement applied to them over the past week on a four-point Likert scale ranging from 0 = *not at all* to 3 = *almost always*. Scores for each subscale were summed and multiplied by 2, with higher scores indicating more distress. (26) Reliability for the anxiety (α = .67), stress (α = .87) and depression (α = .90) subscales were adequate to excellent.

Psychological adjustment to a cancer diagnosis was assessed using the Constructed Meaning Scale **(**CMS). The 8 item CMS measures a patients' cognitive response to being diagnosed with a life-threatening illness (27) on a 4-point Likert scale ranging from 1 = *strongly disagree* to 4 = *strongly agree*. Scores on the CMS reflect ability to construct a positive outlook regarding the effect that cancer has or will have on their future, their relationships, and their sense of self. Internal consistency in the current study was good (α = .77).

Satisfaction with healthcare

Nine items were created by the researchers to assess patients' satisfaction with their health care in terms of the referral process, speed of diagnosis, speed of test results, the hospital where they were treated and the doctors and nurses, the emotional and physical support they receive in hospital and finally, and their medical care overall. Degree of satisfaction with each item was reported on a 5-point Likert scale ranging from 1 = *very dissatisfied* to 5 = *very satisfied*. Data and participant feedback from the pilot phase were examined to ensure items were clear and relevant and excellent internal consistency for the measure was evident (α = .92). Items were averaged to create a mean score.

Quality of life

Regional and remote cancer patients' experiences

Multidimensional QoL was measured using the 35-item Assessment of Quality of Life 8 Dimension instrument (AQoL-8D)(28). Participants responded on a 5-point Likert scale based on aspects of QoL during the past week. Responses are coded so that lower scores reflect poorer QoL on two psychometrically derived dimensions reflecting physical and psychological wellbeing. Internal reliability was evident for physical (α = .64) and psychological (α = .92) dimensions in the current study.

Supportive care needs

Unmet need was measured using the Supportive Care Needs Survey Short Form-34 (SCNS-SF34). (29) The scale assesses patient need for support across five domains including physical and daily living, psychological, health systems and information, patient care and support, and sexuality with a single item regarding financial needs. Responses were coded: 0 (*no need/not applicable/need satisfied*), 1 (*low need*), 2 (*moderate need*), or 3 (*high need*) and means calculated resulting in six continuous variables reflecting the degree of need in each domain. Subscales showed excellent internal reliability (physical and daily living needs α = .86; psychological needs α = .94; health system and information needs α = .95; patient care and support needs α = .88; sexuality needs α = .87).

Analysis

Data analyses were carried out in SPSS Version 26. (30) Frequencies and percentages were calculated for patient responses to each NCCI item. Demographics and area-level characteristic differences in the likelihood of reporting *yes* to a NCCI item were examined using chi-square statistics. A family-wise error rate adjustment was applied to constrain the chance of Type 1 errors to 5%. One-way analyses of variance (ANOVA) were used to identify group differences in NCCI factor scores and psychosocial outcomes Pearson's point biserial correlations assessed whether age was associated with NCCI items and factors. Where group differences were significant, post-hoc contrasts were applied to compare each category against others. Odds ratios (OR) and 95% confidence intervals (CI) were reported for contrasts involving NCCI items. Associations between factor scores and health/psychosocial variables were assessed using a series of correlations with coefficients graphed and compared using a Fisher's *z*-test. Missing data were excluded from analyses in a pairwise manner.

RESULTS

Sample characteristics

Participant ages ranged from 26 to 93 (M = 64.6 , SD = 11.18) and 47.3% of participants identified as female and 52.7% as male. Most participants were born in Australia (80.5%), with the remainder born in the UK (9.9%), New Zealand (4.7%), and other countries (4.9%). Most participants reported low income with 64.8% reporting a household income under \$50,000 a year (i.e., the median yearly gross income in Australia). Most patients were not fully covered by private health insurance (81.5%) and the majority lived in inner (44.0%) or outer (42.5%) regional areas marked by high levels of socio-economic disadvantage (i.e., 66.5% were in the lowest socio-economic quintiles). The most common primary cancers were breast (19.3%), head and neck (14.3%), and skin (12.6%). – see Table 3. Referenced to population statistics available through the Queensland Cancer Registry, the current sample was representative of the non-metropolitan Queensland cancer population in terms of gender, age, and country of birth. However, patients with skin cancer were under-represented (24.5% in population) and patients with head and neck cancer were over-represented (5.8% in population). At the time of data collection, time since diagnosis for each participant ranged between and 33.7 years and 1 day (Median = 211 days), with 64% of participants diagnosed within the previous 12 months.

Table 3. Participant characteristics and responses to NCCI items with chi-square and ANOVA group comparisons.

		Communication and patient involvement					**Provision of information and services**				
	Total n (%)^	Views on treatment n (%)	Involved in decisions n (%)	Side effects explained n (%)	Understand Explanation n (%)	Factor Score M (SD)	Written info on type of cancer n (%)	Assessment and care plan n (%)	Clinical nurse support n (%)	Written info on side effects n (%)	Factor Scor M (SD)
Gender		$\chi^2 = 2.69$	$\chi^2 =1.30$	$\chi^2 = 0.32$	$\chi^2 =0.10$	$F = 2.15$	$\chi^2 =7.88$*	$\chi^2 =0.23$	$\chi^2 =1.05$	$\chi^2 =1.46$	$F = 2.92$
Female	**245 (52.7%)**	147 (63.4%)	149 (63.4%)	156 (65.5%)	234 (97.5%)	1.17 (0.43)	163 (70.3%)	73 (36.3%)	157 (71.7%)	199 (86.9%)	1.36 (0.46)
Male	**273 (47.3%)**	147 (56.1%)	165 (58.4%)	182 (67.9%)	263 (97.0%)	1.11 (0.43)	152 (58.2%)	86 (38.6%)	160 (66.4%)	209 (82.9%)	1.21 (0.48)
Education		$\chi^2 = 16.61$*	144 (68.2%)	$\chi^2 = 9.70$*	$\chi^2 = 0.84$	$F = 9.24$	$\chi^2 = 3.00$	$\chi^2 = 11.44$*	$\chi^2 = 6.39$	$\chi^2 = 2.65$	$F = 7.46$*
Middle school (yr 10)	**217 (42.3%)**	146 (70.2%)	41 (55.4%)	155 (73.1%)	205 (96.7%)	1.23 (0.42)	141 (68.1%)	85 (47.0%)	141 (75.8%)	176 (86.7%)	1.27 (0.48)
Senior school (yr 12)	**78 (15.1%)**	39 (53.4%)	117 (55.2%)	41 (53.9%)	76 (98.7%)	1.05 (0.42)	44 (57.9%)	17 (28.3%)	47 (64.4%)	55 (78.6%)	1.07 (0.47)
Trade/Tertiary	**218 (42.5%)**	107 (51.4%)	$\chi^2 = 0.06$	139 (65.3%)	211 (97.2%)	1.08 (0.42)	128 (62.4%)	57 (31.8%)	127 (64.8%)	172 (84.7%)	1.12 (0.46)
> median income		$\chi^2 = 0.03$	182 (59.7%)	$\chi^2 = 0.06$	$\chi^2 = 2.17$	$F = 0.09$	$\chi^2 = 0.24$	$\chi^2 = 0.44$	$\chi^2 = 1.46$	$\chi^2 = 1.66$	$F =0.01$
Yes	**318 (65.3%)**	73 (57.5%)	144 (68.2%)	84 (67.2%)	126 (99.2%)	1.14 (0.40)	81 (65.3%)	37 (34.9%)	77 (66.4%)	103 (88.8%)	1.17 (0.47)
No	**169 (34.7%)**	172 (58.3%)	78 (60.9%)	204 (66.0%)	301 (96.8%)	1.13 (0.44)	189 (62.8%)	100 (38.6%)	200 (72.5%)	248 (83.8%)	1.17 (0.48)
Born in Australia		$\chi^2 = 0.01$	$\chi^2 = 0.15$	$\chi^2 =0.59$	$\chi^2 = 1.62$	$F =0.18$	$\chi^2 =0.55$	$\chi^2 = 0.15$	$\chi^2 =0.43$	$\chi^2 = 0.85$	$F = 0.02$
Yes	**413 (80.5%)**	233 (59.6%)	238 (60.3%)	261 (65.6%)	387 (96.8%)	1.32 (0.44)	246 (63.2%)	127 (38.0%)	248 (69.5%)	322 (85.4%)	1.17 (0.48)
No	**100 (19.5%)**	58 (59.8%)	63 (62.4%)	71 (69.6%)	104 (99.0%)	1.15 (0.42)	66 (67.3%)	30 (35.7%)	64 (66.0%)	80 (81.6%)	1.16 (0.45)
Full PHI cover		$\chi^2 = 0.86$	$\chi^2 = 0.44$	$\chi^2 = 0.10$	$\chi^2 = 0.96$	$F = 0.26$	$\chi^2 = 0.32$	$\chi^2 = 0.05$	$\chi^2 = 3.38$	$\chi^2 = 0.85$	$F = 0.01$
Yes	**91 (18.5%)**	55 (64.7%)	56 (64.4%)	57 (65.5%)	85 (98.8%)	1.16 (0.24)	55 (67.1%)	27 (36.0%)	48 (60.0%)	73 (88.0%)	1.17 (0.47)
No	**400 (81.5%)**	224 (59.3%)	233 (60.5%)	261 (67.3%)	380 (96.9%)	1.37 (0.44)	242 (63.7%)	120 (37.4%)	247 (70.6%)	308 (83.9%)	1.17 (0.48)
Cancer Site		$\chi^2 = 4.97$	$\chi^2 = 8.65$	$\chi^2 = 2.59$	$\chi^2 = 1.37$	$F = 2.29$*	$\chi^2 = 29.65$*	$\chi^2 = 2.81$	$\chi^2 = 46.11$*	$\chi^2 = 17.43$*	$F = 8.03$*
Breast	**100 (19.3%)**	65 (68.4%)	66 (68.0%)	60 (61.9%)	97 (98.0%)	1.23 (0.43)	78 (80.4%)	33 (41.3%)	87 (92.6%)	84 (92.3%)	1.36 (0.39)
Skin	**65 (12.6%)**	38 (59.4%)	32 (50.8%)	39 (61.9%)	62 (95.4%)	1.05 (0.46)	29 (44.6%)	19 (34.5%)	27 (48.2%)	43 (69.4%)	0.97 (0.54)
Head & Neck	**74 (14.3%)**	39 (54.2%)	48 (66.7%)	51 (68.9%)	71 (97.3%)	1.14 (0.42)	37 (52.9%)	26 (44.8%)	39 (66.1%)	60 (85.7%)	1.16 (0.48)
Prostate	**64 (12.3%)**	38 (62.3%)	43 (67.2%)	43 (68.3%)	62 (98.4%)	1.20 (0.41)	47 (75.8%)	20 (37.7%)	47 (81.0%)	49 (80.3%)	1.25 (0.45)
Other	**215 (41.5%)**	114 (56.4%)	116 (56.3%)	145 (69.4%)	205 (97.2%)	1.10 (0.24)	124 (62.3%)	61 (34.3%)	117 (60.6%)	172 (87.3%	1.12 (0.46)
TOTAL	**518 (100%)**	294 (59.5%)	305 (60.8%)	338 (66.8%)	498 (97.3%)	1.14 (0.43)	316 (64.0%)	159 (37.5%)	317 (68.9%)	408 (84.8%)	1.17 (0.47)

PHI – Private Health Insurance. n (%) = number and percentage of participants in each demographic category responding yes to item, M (SD) = Mean and SD reported for factor scores, ^ valid percent calculated based on non-missing responses to this item, *= $p < .05$ (applying family-wise error rate adjustment for multiple χ^2 tests)

Table 3 cont. Participant characteristic and responses to NCCI items with chi-square and ANOVA group comparisons.

		Communication and patient involvement					**Provision of information and services**				
	Total n (%)	Views on treatment n (%)	Involved in decisions n (%)	Side effects explained n (%)	Understand explanation n (%)	Factor Score M (SD)	Written info on type of cancer n (%)	Assessment and care plan n (%)	Clinical nurse support n (%)	Written info on side effects n (%)	Factor Score M (SD)
SEIFA Quintile		χ^2 = 5.29	χ^2 = 3.45	χ^2 = 4.04	χ^2 = 4.59	*F* = 0.61	χ^2 = 1.30	χ^2 = 0.90	χ^2 = 5.58	χ^2 = 2.64	*F* = 0.41
1st (lowest)	**185 (36.0%)**	115 (64.2%)	110 (60.8%)	129 (71.3%)	180 (98.4%)	1.17 (0.43)	113 (63.8%)	56 (37.3%)	118 (71.1%)	154 (88.0%)	1.20 (0.46)
2nd	**155 (30.3%)**	89 (60.5%)	93 (61.2%)	99 (65.6%)	147 (96.1%)	1.12 (0.45)	98 (65.8%)	49 (38.9%)	90 (65.7%)	122 (82.4%)	1.16 (0.49)
3rd	**112 (21.9%)**	59 (57.3%)	59 (56.75)	65 (60.2%)	105 (95.5%)	1.09 (0.44)	66 (63.5%)	36 (40.9%)	71 (72.4%)	82 (83.7%)	1.17 (0.49)
4th	**54 (10.6%)**	25 (47.2%)	37 (69.8%)	37 (68.5%)	54 (100.0%)	1.12 (0.39)	32 (59.3%)	17 (34.7%)	31 (64.6%)	42 (82.4%)	1.13 (0.48)
5th (highest)	**5 (1.0%)**	3 (60.0%)	2 (40.0%)	3 (60.0%)	5 (100.0%)	1.04 (0.43)	4 (80.0%)	1 (25.0%)	1 (25.0%)	3 (75.0%)	1.02 (0.041)
ARIA		χ^2 = 5.22	χ^2 = 3.35	χ^2 = 4.55	χ^2 = 2.66	*F* = 0.48	χ^2 = 0.99	χ^2 = 4.67	χ^2 = 2.47	χ^2 = 0.94	*F* = 0.99
Major city	**24 (4.7%)**	9 (37.5%)	14 (58.3%)	13 (54.2%)	24 (100.0%)	1.03 (0.44)	17 (70.8%)	10 (41.7%)	14 (63.6%)	20 (90.9%)	1.17 (0.46)
Inner regional	**225 (44.0%)**	128 (60.7%)	140 (63.6%)	154 (70.3%)	216 (97.3%)	1.15 (0.38)	139 (64.7%)	61 (33.5%)	133 (68.6%)	177 (83.5%)	1.16 (0.44)
Outer regional	**217 (42.5%)**	128 (61.0%)	125 (60.4%)	140 (65.7%)	207 (96.3%)	1.12 (0.47)	129 (62.3%)	76 (43.4%)	134 (68.0%)	172 (85.1%)	1.19 (0.52)
Remote	**23 (4.5%)**	13 (61.9%)	12 (54.5%)	14 (66.7%)	23 (100.0%)	1.14 (0.44)	13 (61.9%)	7 (38.9%)	14 (66.7%)	16 (84.2%)	1.17 (0.50)
Very remote	**22 (4.3%)**	13 (61.9%)	10 (45.5%)	12 (54.5%)	21 (100.0%)	1.08 (0.43)	15 (68.2%)	5 (27.8%)	16 (84.2%)	18 (85.7%)	1.18 (0.48)

n(%) = number and percentage of participants in each area-level category responding yes to item, M (SD) = Mean and SD reported for factor scores,
*= *p* < .05 (applying family-wise error rate adjustment)

Communication and patient involvement

Participants reported that their views were taken into account when their team of doctors and nurses were discussing their treatment 59.5% of the time (Table 3). Those with middle school education or lower were twice as likely to report having their views taken into account in treatment decisions (OR = 2.22, CI = 1.49 – 3.33) compared to those with senior high school or trade/tertiary level education. Older patients were slightly more likely to report that their views were taken into account by doctors and nurses when deciding on treatment ($r = .11$, $p = .02$). Similarly, 60.8% of participants felt they were involved in decisions about their care and treatment as much as they would have liked, however, this did not vary according to individual characteristics.

Most participants reported understanding the explanation of “what was wrong with them” upon diagnosis (97.3%) and this did not differ significantly according to individual characteristics. More than half of the patients (66.8%) reported that the possible side-effects of their treatment were explained to them in a way they could understand. Those with middle school education or lower were 1.5 times more likely to report having side effects explained to them in a way that they understood compared to those with trade/tertiary level education (OR = 1.50, CI = 1.14 – 1.96) and those with senior level education were less likely to report this compared to those with trade/tertiary level education (OR = 0.65, CI = 0.46 – 0.90).

Group differences were evident in participants’ scores on the communication and patient involvement factor with patients possessing middle school level education (M = 1.23, SD = 0.42) reporting higher scores than those with trade/tertiary level education (M = 1.08, SD = 0.42), t (509) = 42.75, p <.001, d = 0.36, or those with senior school level education (M = 1.05, SD = 0.42), t (509) = 21.88, p <.001, d = 0.43. When compared with all other cancer types, patients with breast (M = 1.23, SD = 0.43), t (512) = 28.75, p <.001, d = 0.28, and prostate (M = 1.20, SD = 0.41), t (512) = 22.40, p <.001, d = 0.17 cancer reported higher

scores on the communication and patient involvement factor, while those with skin (M = 1.05, SD = 0.46), t (512) = 19.75, *p* <.001, *d* = 0.22 and head and neck (M = 1.14, SD = 0.42), t (512) = 22.83, *p* <.001, *d* = 0.01 cancers reported lower scores than those with other cancer types.

Provision of information and services

Sixty-four percent of participants were given written information about the type of cancer they had. Females were 1.69 (CI = 1.16 – 2.46) times as likely to report receiving this information when compared to males. Patients with breast cancer were 2.41 (CI = 1.39 – 4.42) times more likely, and those with skin cancer were 0.49 (CI = 0.28 – 1.18) times as likely to receive written information about the type of cancer they had compared to those with other cancers. The majority of patients reported being given written information about the side effects of treatment (84.8%) with those with skin cancer less likely to receive this information compared to those with other cancer types 0.33 (CI= 0.17 – 0.65).

Only 37.5% of participants reported receiving a written assessment and care plan. Those with middle school education or lower were almost two times more likely to report receiving an assessment and care plan (OR = 1.90, CI = 1.23 – 2.91) compared to those with senior high school or trade/tertiary level education. Over two thirds of patients reported being given the name of a clinical nurse specialist to support them through treatment (68.9%), however, patients with breast cancer were 8.07 (CI = 3.55 – 18.37) times more likely, and patients with prostate cancer patients were 2.77 (CI = 1.36– 5.68) times more likely, to be offered this service compared to participants with other types of cancer.

Those with middle school level education or lower (M = 1.27, SD = 0.48) reported higher scores on the provision of service and information factor than those with trade/tertiary level education (M = 1.12, SD = 0.47), t (509) = 39.71, *p* <.001, *d* = 0.32 or those with senior school level education (M = 1.07, SD = 0.46), t (509)= 20.28, *p* <.001, *d* = 0.42. When compared with all other cancer types, patients with breast (M = 1.36, SD = 0.39), t (99) =

34.47, *p* <.001, *d* = 0.54 or prostate (M = 1.25, SD = 0.45), t (63) = 22.42, *p* <.001, *d* = 0.19 cancer reported higher scores on the provision of information and services factor, while those with skin (M = 0.97, SD = 0.54), t (64) = 14.52, *p* = <.001, *d* = 0.46 or head and neck (M = 1.16, SD = 0.48), t (73) = 20.73, *p* <.001, *d* = 0.03 cancers reported lower scores than those with other cancer types. Area-level characteristics (i.e., remoteness or SEIFA) were not significantly associated with single items or factor scores reflecting provision of information and services (see Table 3). Mean levels of physical QoL (*F*(4) = 5.94, *p* < .001), anxiety (*F*(4) = 3.42, *p* = .009), physical and daily living (*F*(4) = 5.02, *p* < .001) and sexuality (*F*(4) = 3.34, *p* = .010), supportive care needs were significant different across cancer types. Post hoc comparisons with a Bonferroni adjustment showed that breast cancer survivors (*M* = 4.48, *SD* = 4.10) reported significantly lower levels of anxiety than those in the 'other' cancer group (*M* = 6.63, *SD* = 5.94), *p* = .015 and those with prostate cancer (*M* = .50, *SD* = .68) and breast cancer (*M* = .59, *SD* = .68) reported lower physical and daily living supportive care needs than those in the 'other' cancer group (*M* = .89, *SD* = .82), *p* = .004 and p = .012 respectively. Those with prostate cancer (*M* = .64, *SD* = .92) also reported significantly higher sexuality supportive care needs than those with skin (*M* = ..29, *SD* = .60.), *p* = .039 or head and neck cancer (*M* = .28, *SD* = .61), *p* = .020 and those with breast (*M* = 75.73, *SD* = 10.25) and prostate cancer (*M* = 70.88, *SD* = 10.81) report significantly higher physical QoL compared to those in the 'other' cancer group (*M* = 70.88, *SD* = 10.81), both *p* < .001.

Associations between NCCI factor scores and health and psychosocial variables

Both communication and patient involvement and provision of information and services factors shared significant positive associations with QoL, satisfaction with health care and constructed meaning (see Figure 2). They were also both associated with lower supportive care needs in most cases, the strongest associations being with health system and information needs. The communication and patient involvement factor was moderately associated with greater psychosocial QoL (*r* = .30, *p* <.001) and satisfaction with healthcare

($r = .29$, $p <.001$) as well as lower levels of unmet 'health systems and information' ($r = -.39$, $p <.001$). and 'patient care' ($r = .35$, $p <.001$) needs and lower cancer threat appraisal ($r = .31$, $p <.001$). The provision of information and services factor had a weaker pattern of associations though still moderately predicted lower levels of unmet 'health systems and information' ($r = -.32$, $p <.001$) and 'patient care' ($r = -.23$, $p <.001$) needs as well as greater satisfaction with healthcare ($r = .23$, $p <.001$). The communication and patient involvement factor shared significantly stronger associations with higher psychosocial QoL ($z = 2.03$, $p = .042$), and lower levels of unmet need in terms of psychosocial support ($z = 2.05$, $p =.040$) and patient care ($z = 2.00$, $p =.046$). Communication and patient involvement was associated with lower stress and anxiety, while provision of information and services was not (see Figure 2).

Area-level characteristics (i.e., remoteness or SEIFA) were not significantly associated with single items or scores on either NCCI factor (see Table 3).

DISCUSSION

The goal of delivering equitable patient-centered cancer care is a corner stone of cancer control plans and care guidelines. (6,7,9,12) The present study suggests that the NCCI patient experience indicators have validity and potential as a tool for monitoring and benchmarking the quality of cancer care relating specifically to patient understanding and involvement. Importantly, this brief tool discriminated between different aspects of patient experience for those dislocated from their home during treatment and identified characteristics associated with a poorer experience. While it was almost universal for patients to recall understanding the explanation of their treatment, and most people reported that treatment side effects were explained and supported with written information, only a minority received a written assessment and care plan. Further, patient experience varied by clinical and sociodemographic characteristics suggesting that there is work to be done on better understanding what influences care, and how we might intervene.

Regional and remote cancer patients' experiences

From a construct perspective, the patient experience as measured by the NCCI indicators presented along two key dimensions: 1) communication and patient involvement and 2) provision of information and services. For both dimensions, the strong association with health system and information needs provides evidence of convergent validity. The closer connection between communication and patient involvement and QoL and psychosocial outcomes intuitively makes sense given the important role of the interpersonal relationships between the health care teams and patients, as well as the self-efficacy and personal agency that evolves from patient's involvement in their health care. (31) These associations may be bi-directional. Patients with lower psychological distress have a higher capacity to absorb information, take part in decision making, benefit from communications with healthcare professionals (32,33) and are subsequently more likely to report satisfaction with this element of their care. (34) In fact this may be reflected in the current findings that breast cancer patients in this sample reported both lower levels of anxiety and better patient experiences compared to those with other cancers. Those individuals who are psychologically vulnerable or have poorer QoL likely need stepped up care to achieve optimal outcomes. (35)

Despite suggestions than remote living is associated with poorer experiences for cancer survivors, area level factors were not associated with NCCI outcomes. Rather, differences in patient experiences according to cancer were apparent. Notably, breast and prostate cancer patients were more likely to receive clinical nurse support compared to skin and head and neck cancer patients. This may reflect the different resources and services available for specific cancers, for example, the introduction of the specialist nurse role for breast cancer patients, (36) and more recently prostate cancer patients. (37) While a specialist nurse appears to greatly enhance patient experience, (38) providing this for all cancer types is likely a resourcing challenge especially for regional and remote health services. Models that incorporate telehealth and that span broadly across multiple cancer types or chronic disease may be needed. (39) Higher education appeared to be associated with less communication and patient involvement and information and services. The reasons for this are unclear however it may be that health professionals assume these patients require less support or alternatively that people with more education have greater expectations in this domain of care.

As the aim of the present study was to provide specific insight into the experiences of regional and remote cancer patients, caution should be in applied in generalising these findings to urbanised populations. Since the survey is cross-sectional we cannot assume causality; and the data is self-reported and was not able to be verified by observational data or care records. However, this large, representative sample was recruited from a statewide jurisdiction and so likely represents the actual experience of patients from regional and remote Australia. Although regional and remote areas tend to be marked by higher socio-economic disadvantage in Australia (23), the particularly low SES status of this sample may be due to recruiting participants through free or low-cost accommodation services. Low levels of variance in area-level disadvantage in this sample may have impeded the detection of significant effects. These alternative hypotheses should be the subject of future research with samples not in receipt of such services. Although the aim of the current research was to assess patient experiences using a metric published by a National governing body, it is important to note that several valid measures of patient experience covering different aspects of patients' care and support needs exist (10, 11, 29) and future research will benefit from their inclusion.

The present results outline the patient experience for a rural and regional population who are at risk of fragmented or poorly coordinated care. Patients who report better communication with their health care team and more involvement have better QoL, less stress and anxiety, and lower threat. Fulfilling the NCCI indicators connects to lower unmet need in health services and information. Cancer care services that ensure these indicators are met are better placed to provide an optimal cancer experience and improved patient-reported outcomes.

The NCCI presents as a useful and valid tool for assessing the patient experience. The aspect of care that appears most crucial is communication and involvement with the health care team. Strategies to optimize this for regional and remote patients need to be a cancer control priority.

Figure Captions:

Figure 1. Recruitment flowchart

Figure 2. Visual comparison of the correlation co-efficients between each health/psychosocial variable and each factor.

Declarations

Author Contribution Statement

JD, BG, JFA, SM, FCW, MJI, NR, LZ, AR, & SKC contributed to the study conception and design. Material preparation and data collection were conducted by BG, FCW, AR, & LZ and analyses were performed by BG and MJI. The first draft of the manuscript was written by JD and SKC and JD, BG, JFA, SM, FCW, MJI, NR, LZ, AR, & SKC provided substantial contributions in revising the manuscript and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

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Data sharing statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Ethical Approval

The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of Southern Queensland (Ethics approval number: ref. H17REA152).

Consent to participate

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

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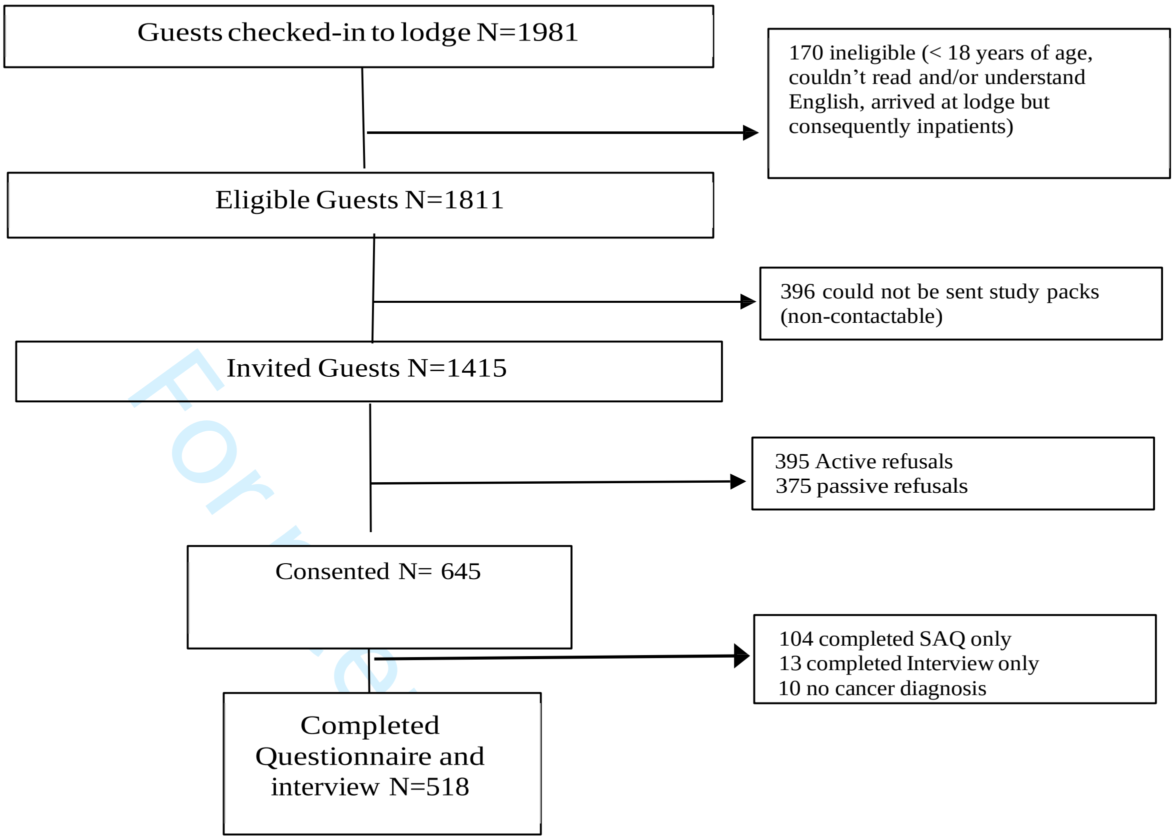
Figure 1. Recruitment flowchart



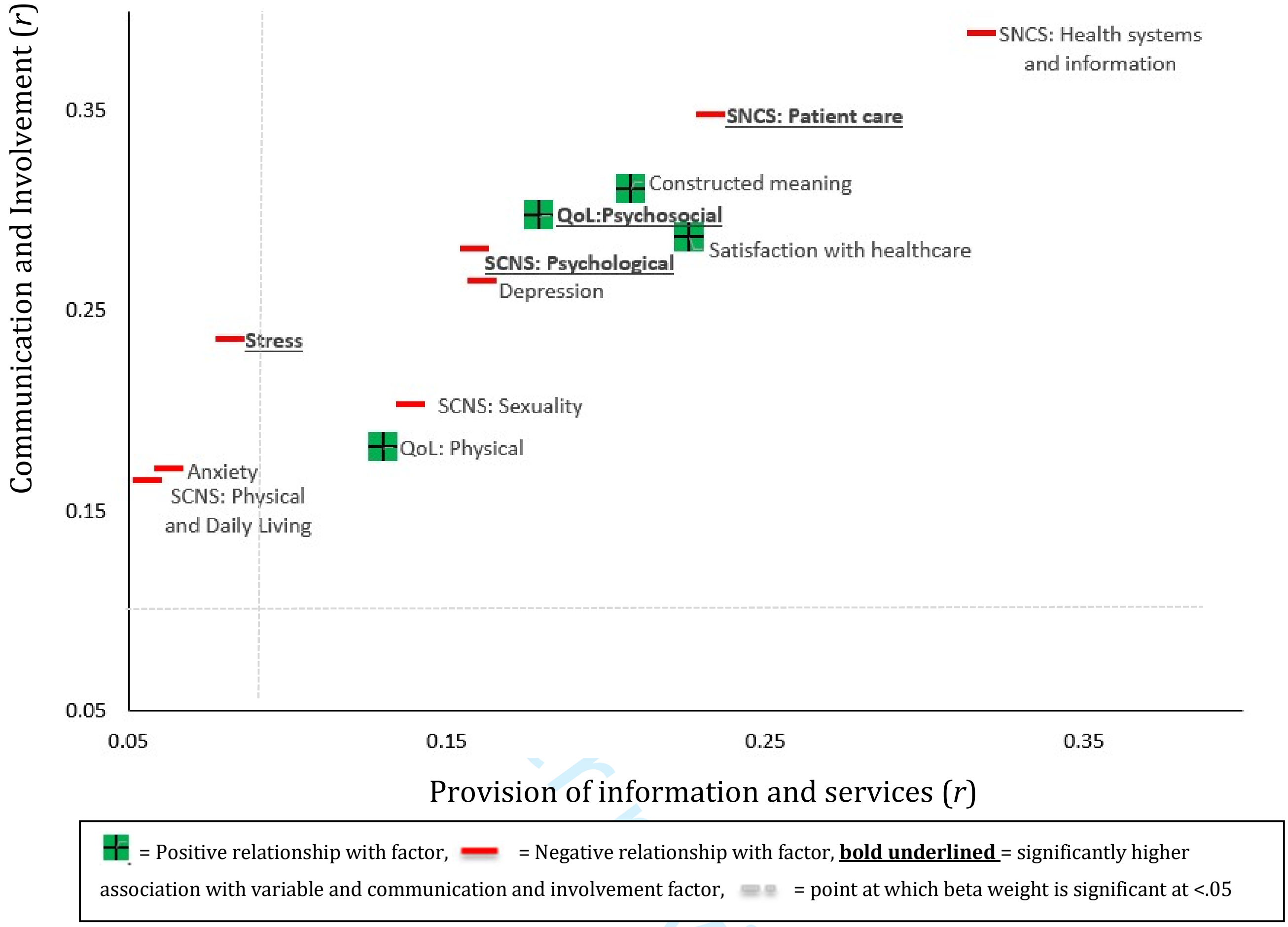


Figure 2. Visual comparison of the correlation co-efficients between each health/psychosocial variable and each factor.

Applying National Cancer Control Indicators to Regional and Remote Cancer Patients' Experiences Jeff Dunn, Belinda C Goodwin (belindagoodwin@cancerqld.org.au), Joanne F. Aitken, Sonja March, Fiona Crawford-Williams, Michael J. Ireland, Nicholas Ralph, Leah Zajdlewicz, Arlen Rowe, and Suzanne K. Chambers.
University of Southern Queensland & Cancer Council Queensland

Supplementary Table 1. Frequencies and percentages^ of responses to NCCI – Patient Experience Items and grouping of binary responses, n (%).

	Yes, I completely understood it	**Yes, I understood some of it**	**No**	**I can't remember**		**Missing**
When you were told you had cancer, did you understand the explanation of what was wrong with you?	345 (66.7%)	153 (29.4%)	14 (2.7%)	5 (1.0%)		1 (0.19%)
	Yes, and it was easy to understand	**Yes, and it was difficult to understand**	**No**	**I did not need written information**	**I don't know/ can't remember**	**Missing**
When you were told you had cancer, were you given written information about the type of cancer you had?	262 (51.3%)	54 (10.6%)	134 (26.2%)	44 (8.6%)	17 (3/3%)	7 (1.4%)
	Yes	**No**	**I don't know/ can't remember**			**Missing**
Have you been offered a written assessment and care plan	159 (31.0%)	265 (51.7%)	89 (17.3%)			5 (1.0%)
	Yes	**No**	**I don't know/ can't remember**			**Missing**
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	317 (61.8%)	143 (27.9%)	53 (10.2%)			5 (1.0%)
	Yes, definitely	**Yes, to some extent**	**No, but I would have liked to be more involved**	**I don't know/can't remember**		**Missing**
Were you involved as much as you wanted to be in decisions about your care and treatment?	305 (59.2%)	161 (31.3%)	36 (6.9%)	13 (2.5%)		3 (0.6%)

^valid percentage reported except for missing column, calculated based on non-missing data ---- = coded as yes, ---- = coded as no, no border = treated as missing

Applying National Cancer Control Indicators to Regional and Remote Cancer Patients' Experiences Jeff Dunn, Belinda C Goodwin (belindagoodwin@cancerqld.org.au), Joanne F. Aitken, Sonja March, Fiona Crawford-Williams, Michael J. Ireland, Nicholas Ralph, Leah Zajdlewicz, Arlen Rowe, and Suzanne K. Chambers.
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Supplementary Table 1. (Cont.)

	Yes, definitely	**Yes, to some extent**	**No**	**I didn't know my treatment was being discussed …**	**I don't know/ can't remember**	**Missing**
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	294 (57.8%)	152 (29.2%)	31 (6.1%)	17 (2.9%)	15 (2.8%)	9 (1.7%)
	Yes, definitely	**Yes, to some extent**	**No**	**I did not need an explanation**	**I don't know/ can't remember**	**Missing**
Were the possible side effects of treatment(s) explained in a way you could understand?	338 (65.5%)	136 (26.4%)	30 (5.8%)	2 (0.4%)	10 (1.9%)	2 (0.4%)
	Yes, and it was easy to understand	**Yes, and it was difficult to understand**	**No**	**I don't know/ can't remember**		**Missing**
Before you started your treatment, were you given written information about the side effects of treatment(s)?	354 (69.4%)	54 (10.6%)	73 (14.3%)	29 (5.7%)		8 (1.5%)

^valid percentage reported except for missing column, calculated based on non-missing data - - - = coded as yes, - - - = coded as no, no border = treated as missing

Note: To assess whether time since diagnosis was associated with non-response (i.e., no response or I don't know/ don't remember response), point bi-serial correlations were conducted between non-response and days since diagnosis. One weak association whereby those who were further past diagnosis were less likely to recall/provide a response to the NCCI item "Were you involved as much as you wanted to be in decisions about your care and treatment" (*r* = .130, *p* =.004)

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	**Item #**	**Recommendation**	**Reported on page #**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5,6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7-13
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	7-13
Bias	9	Describe any efforts to address potential sources of bias	13 & 23
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	13
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	13
		(*b*) Describe any methods used to examine subgroups and interactions	13
		(*c*) Explain how missing data were addressed	14
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	-
		(*e*) Describe any sensitivity analyses	-
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7 (figure)
		(b) Give reasons for non-participation at each stage	7 (figure)
		(c) Consider use of a flow diagram	7 (figure)
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	14
		(b) Indicate number of participants with missing data for each variable of interest	15 – 16 (tables)
Outcome data	15*	Report numbers of outcome events or summary measures	15 – 16 (tables)
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	-
		(*b*) Report category boundaries when continuous variables were categorized	15-16
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	18-20
Discussion			
Key results	18	Summarise key results with reference to study objectives	21
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	22
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	21,22
Generalisability	21	Discuss the generalisability (external validity) of the study results	22
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	2

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.