The EORTC Quality of Life Questionnaire for cancer patients (QLQ-C30): Australian general population reference values

Rebecca Mercieca-Bebber[1], Daniel SJ Costa[2], Richard Norman[3], Monika Janda[4], David P Smith[5], Peter Grimison[6], Eva-Marie Gamper[7], Madeleine T King[8]

The known: The EORTC QLQ-C30, the core module of the EORTC Quality of Life Questionnaire suite, is one of the most widely used such questionnaire for people with cancer. As quality of life scores vary with language and culture, country-specific normative values are needed.

The new: We report the first Australian general population reference values for the EORTC QLQ-C30. They will assist interpretation of scores for Australian cancer patients and survivors, and highlight the influence of psychological distress and common comorbid conditions, particularly arthritis and rheumatism, on quality of life.

The implications: Australian QLQ-C30 general population reference values provide appropriate benchmarks for assessing the impact of disease and treatment on Australians with cancer.

Abstract

Objectives: To generate Australian general population reference values for the EORTC Quality of Life Questionnaire for cancer patients (QLQ-C30); to compare Australian values with published EORTC general population reference values, and to explore associations between socio-demographic and health characteristics and QLQ-C30 subscale scores.

Design: Analysis of responses to cross-sectional, online survey (QLQ-C30), March 2015 – February 2016, and supplementary health-related and socio-demographic questions.

Setting, participants: 1979 people quota-sampled from a national online survey panel to be representative of the Australian general population by age and sex.

Main outcome measures: Mean QLQ-C30 subscale scores, adjusted for socio-demographic characteristics and comorbid conditions, by sex and age group.

Results: Data for 1821 participants were analysed (92% completion rate); 924 (50.7%) were women. Higher psychological distress was associated with worse outcomes on all QLQ-C30 subscales. Better self-reported general health was associated with better global quality of life and better functioning (except cognitive functioning), and less fatigue, pain, dyspnoea and insomnia. Having arthritis or rheumatism was associated with poorer global quality of life, and poorer physical, role and social functioning, and with more fatigue, pain, insomnia, diarrhoea, and financial difficulties. Although differences between Australian QLQ-C30 subscale scores and EORTC general population values were clinically trivial, the Australian values are more accurate benchmarks for QLQ-C30 results from Australians with cancer.

Conclusions: Our Australian QLQ-C30 reference values provide normative benchmarks that facilitate interpretation of data for Australians with cancer in terms of burden of disease and its treatment. In survivorship studies and studies without pre-disease baseline data, comparisons with reference values can indicate the extent to which people have returned to better levels of health.

One of the most widely employed questionnaires for patient-reported outcomes in cancer research is the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30), used in more than 3000 studies since 1993.[1] It includes 30 questions in 15 subscales relevant to people with cancer: five distinct aspects of functioning (physical, role, emotional, cognitive, social), eight symptoms (fatigue, nausea/vomiting, pain, dyspnoea, insomnia, appetite loss, constipation, diarrhoea), financial difficulties, and global health/quality of life.[2]

An individual's QLQ-C30 score often fluctuates during the course of their disease, both in response to improvement or deterioration of their health condition or key symptoms, and as the patient adapts to living with their condition or symptom (response shift).[3] Interpreting QLQ-C30 data is consequently challenging. QLQ-C30 scores collected during or after an intervention are typically compared with baseline values (if available), but such comparisons may be misleading if the symptom burden of the cancer or the psychological impact of the cancer diagnosis had depressed baseline responses.[4] In such cases, and when baseline assessment is not possible, reference values for the general population are informative comparator data. Age and sex influence patient-reported outcome scores and are therefore key characteristics for general population reference values.[5]

QLQ-C30 general population reference values published by the EORTC have been based on data for participants from Austria, Germany, Denmark, Norway, and the United States.[6] Country-specific values have also been published for Sweden,[4] Norway,[5] Germany,[7] and Denmark;[8] values have not been published for Australia. As Australian population reference values for other patient-reported outcome questionnaires differ from those for other countries,[9,10] it is important that scores for Australian patients with cancer are compared with Australian reference values.

Our primary aim was therefore to derive Australian general population reference values for the QLQ-C30. Our secondary aims were to compare Australian values with EORTC general population reference values, and to explore the association between socio-demographic characteristics and QLQ-C30 subscale scores.

Methods

Participants

Participants were recruited during March 2015 – February 2016 from an Australian national online survey panel (PureProfile; www.pureprofile.com), quota-sampled for representativeness of the Australian general population by age and sex[11] according to

[1]NHMRC Clinical Trials Centre, University of Sydney, Sydney, NSW. [2]Pain Management Research Institute, University of Sydney, Sydney, NSW. [3]Curtin University, Perth, WA. [4]Centre for Health Services Research, Queensland University of Technology, Brisbane, QLD. [5]Cancer Council NSW, Sydney, NSW. [6]Chris O'Brien Lifehouse, Sydney, NSW. [7]Medical University of Innsbruck, Innsbruck, Austria. [8]Quality of Life Office, University of Sydney, Sydney, NSW. ✉ madeleine.king@sydney.edu.au • doi: 10.5694/mja2.50207

Australian Bureau of Statistics data[12] current at the time of the survey. Participants who were accepted after answering the age and sex filtering questions and completed the survey received participation credits they could redeem in vouchers or cash (approximate value, $2).

Survey

The content of the survey is reported elsewhere.[11] Data analysed in the study reported in this article included self-reported quality of life during the past week (EORTC QLQ-C30, version 3.0),[13] self-reported general health ("In general, would you say your health is: 1) excellent; 2) very good; 3) good; 4) fair; 5) poor?"), self-reported chronic conditions (Charlson Comorbidity Index),[14] psychological distress (Kessler Psychological Distress Scale, K10),[15] and data for selected socio-demographic questions from the Household, Income and Labour Dynamics in Australia (HILDA) survey.[16]

Statistical analysis

The survey completion rate was defined as the proportion of people who progressed past the age and sex filtering questions and then completed the survey. Socio-demographic data were compared with corresponding Australian general population reference values from the Australian Bureau of Statistics 2013[12] in χ^2 or one sample t tests as appropriate. K10 scores were compared with data from the 2007 Australian National Health Survey.[15] Chronic condition data were compared with national reference data if available,[17–21] and other socio-demographic data were compared with HILDA wave 10 data.[16]

The EORTC QLQ-C30 was scored according to the scoring manual.[2] This produced scores on 15 subscales (range for each, 0–100), with higher scores indicating better outcomes on global quality of life/health and functioning subscales and worse outcomes on symptom scales and for financial problems.

For self-reported general health and psychological distress, a higher score indicated worse health. There were ten self-reported chronic conditions (Box 1).

We first conducted multiple linear regressions, including socio-demographic variables and chronic conditions as predictors for each QLQ-C30 subscale, to determine which factors predicted QLQ-C30 subscale scores, using bootstrapping (500 replications) to correct for skewed distributions and Bonferroni-adjusted $\alpha = 0.003$ (0.05/15 subscales). We then derived mean QLQ-C30 scores standardised to population characteristics, using regression coefficients from the first analysis to specify a regression equation for each subscale and then adding population means for each predictor. If our survey sample was not representative of the general population, the raw and standardised scores may have differed, and the standardised scores would provide a better representation of general population QLQ-C30 values. This standardisation approach is similar to the direct/indirect standardisation employed in epidemiologic studies, but our approach is more amenable to simultaneous standardisation for multiple variables (including continuous variables).

To determine the clinical significance of differences on each subscale by sex and age group, and between the Australian adjusted mean scores and the EORTC general population values, we applied the thresholds defined by Cocks and colleagues[22] for trivial, small, medium and large differences; this was not undertaken for the subscale "emotional functioning", for which there are no interpretation guidelines.

Multiple linear regression was conducted in Mplus 7.4; all other analyses were performed in SPSS 24 (IBM).

Ethics approval

The study was approved by the University of Sydney Human Research Ethics Committee (reference, 2012/2444).

Results

Of the 2981 individuals who opted to participate in the survey, 1979 were accepted after the age and sex filtering questions and 1821 completed the content relevant to the reported analysis (completion rate, 92%).

The sample was statistically representative of the Australian population in terms of age and sex, but not with respect to other characteristics. K10 psychological distress scores were higher for survey participants than the general population in each age group, particularly younger age groups; for people aged 25–54 years, the mean K10 scores for survey participants indicated "moderate distress", those for the general population "low distress". The self-reported general health of participants aged 40–49 or 50–59 years was somewhat poorer than for the general population, but was better among those aged 70 years or more (Box 1).

Most participants (1075, 59.0%) reported not having any of the listed chronic conditions; the most prevalent among survey participants were arthritis or rheumatism (363, 9.9%), asthma, emphysema or chronic bronchitis (245, 13.5%), and diabetes (173, 9.3%). The proportion of participants ever diagnosed with cancer (9.5%) was higher than the national figure (4.3%) (Box 1).

Predictors of QLQ-C30 subscale scores

Higher psychological distress was associated with worse outcomes on all QLQ-C30 subscales. Having arthritis or rheumatism was associated with poorer global quality of life, physical, role and social functioning, and more fatigue, pain, insomnia, diarrhoea, and financial difficulties. Better self-reported general health was associated with better global quality of life and better functioning (except cognitive functioning), and less fatigue, pain, dyspnoea and insomnia (Box 2).

While the survey sample was representative of the Australian population by age and sex, it was non-representative for most other socio-demographic variables and chronic conditions (Box 1). We therefore adjusted our QLQ-C30 mean scores to derive credible Australian population reference values; the coefficients (with 95% CIs) used for this adjustment are summarised in the online Supporting Information, table 1.

Australian QLQ-C30 reference values, adjusted for socio-demographic characteristics

The adjusted population means were better for women than men on all but four of the QLQ-C30 scales, the exceptions being emotional functioning, fatigue, diarrhoea, and financial difficulties. All differences were of trivial to small clinical significance (Box 3).

Australians aged 70 years or more had the highest mean scores on the global quality of life and on the emotional and cognitive functioning scales, and the lowest pain and insomnia scores. Australians aged 18–29 years had the lowest mean scores for role functioning and the highest scores on the fatigue, pain, appetite loss, constipation, and diarrhoea scales. All differences were clinically trivial or small (Box 4).

1 Socio-demographic and health characteristics of the 1821 survey participants, compared with Australian general population reference values*

Characteristic	Survey sample value	Population value	P
Sex[12]			0.96
Men	897 (49.3%)	49.3%	
Women	924 (50.7%)	50.7%	
Age (years)[12]			0.98
18–29	402 (22.1%)	22.3%	
30–39	325 (17.8%)	17.9%	
40–49	322 (17.7%)	18.0%	
50–59	296 (16.3%)	16.5%	
60–69	241 (13.2%)	12.8%	
70 or older	235 (12.9%)	12.5%	
General health score,[15] mean (SD)[†]			
18–29 years (n = 401)	2.36 (0.94)	2.33 (0.87)	0.61
30–39 years (n = 324)	2.53 (1.01)	2.44 (0.88)	0.16
40–49 years (n = 322)	2.88 (0.95)	2.63 (0.92)	< 0.001
50–59 years (n = 296)	2.94 (1.05)	2.80 (0.95)	0.027
60–69 years (n = 241)	2.97 (0.97)	2.91 (0.94)	0.52
70 years or older (n = 235)	2.94 (0.98)	3.16 (0.92)	0.001
Kessler psychological distress scale (K10),[14] mean (SD)[‡]			
25–34 years (n = 361)	19.9 (8.10)	14.8	< 0.001
35–44 years (n = 305)	19.2 (8.54)	15.0	< 0.001
45–54 years (n = 300)	17.6 (8.01)	14.8	< 0.001
55–64 years (n = 287)	15.7 (6.07)	13.9	< 0.001
65–74 years (n = 269)	14.0 (4.60)	13.1	0.002
75–85 years (n = 85)	14.3 (4.67)	13.1	0.023
All ages (n = 1819)	17.8 (7.53)	14.5	< 0.001
Country of birth[15]			< 0.001
Australia	1349 (74.1%)	79.2%	
Other English-speaking country	270 (14.8%)	9.5%	
Other	201 (11.0%)	11.3%	
Highest level of education[15]			< 0.001
Year 11 or below	297 (16.3%)	27.8%	
Year 12	336 (18.5%)	16.9%	
Bachelor degree	419 (23.0%)	13.5%	
Postgraduate degree	183 (10.1%)	4.0%	
Other (trade certificate, diploma)	585 (32.1%)	37.8%	
Indigenous status[15]			< 0.001
Aboriginal or Torres Strait Islander	152 (8.3%)	3.2%	

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Characteristic	Survey sample value	Population value	P
Marital status[15]			< 0.001
Married (registered)	792 (43.5%)	49.3%	
Separated	55 (3.0%)	3.5%	
Divorced	151 (8.3%)	9.7%	
Widowed	66 (3.6%)	5.5%	
De facto	260 (14.3%)	11.7%	
Never married	497 (27.3%)	20.3%	
Chronic conditions			
Asthma, emphysema, chronic bronchitis	245 (13.5%)	NA	
Arthritis or rheumatism[17]	363 (19.9%)	15.2%	< 0.001
Cancer diagnosed in past 3 years[18]	51 (2.8%)	NA	
Ever diagnosed with cancer[18]	173 (9.5%)	4.3%	< 0.001
Diabetes[19]	169 (9.3%)	6.0%	< 0.001
Digestive problems (such as ulcer, colitis, or gall bladder disease)	130 (7.1%)	NA	
Heart problems (angina, congestive heart failure, coronary artery disease)	106 (5.8%)	NA	
HIV illness or AIDS[20]	8 (0.4%)	0.13%	< 0.001
Kidney disease	29 (1.6%)	NA	
Liver problems	30 (1.6%)	NA	
Stroke[21]	24 (1.3%)	2.0%	0.038
None of these chronic conditions	1075 (59.0%)	NA	
Family member ever diagnosed with cancer	806 (44.3%)	NA	
Admitted to hospital in past 12 months	401 (22.0%)	NA	

NA = population data not available; SD = standard deviation. * Sources for national reference data are included in the "Characteristic" column. † "In general, would you say your health is …?" Responses range from 1, excellent to 5, poor. ‡ K10 data for 18–24 year olds were not available in a format that could be compared with our data; standard deviations were not reported in the national data source. Scores are classified as indicating low (10–15), moderate (16–21), high (22–30), or very high distress (31–50). ◆

QLQ-C30 subscale scores by age and sex group are depicted in the online Supporting Information, figures 1 and 2; reference values by age and sex group, are summarised in the online Supporting Information, table 2.

Differences between Australian population values and EORTC values were clinically trivial (Box 5).

Discussion

We report the first Australian general population reference values for the EORTC QLQ-C30. These values can assist interpretation of QLQ-C30 scores, indicating the added psychological burden caused by cancer and its treatment, for Australians with cancer. They will be particularly useful for studies in which

2 Socio-demographic variables significantly associated (α = 0.003) with better outcomes on EORTC Quality of Life Questionnaire (QLQ-C30) subscales for 1821 survey participants

Scale	Characteristic	Unstandardised regression parameter (95% CI)	P
Global health/quality of life	Age: 18–29 years v 70 or more	5.61 (2.47 to 8.75)	0.002
	Self-reported general health, per point	−11.4 (−12.3 to −10.5)	< 0.001
	Arthritis or rheumatism	−3.67 (−5.53 to −1.81)	< 0.001
	Psychological distress (K10), per point	−0.99 (−1.11 to −0.88)	< 0.001
Physical functioning	Self-reported general health, per point	−3.84 (−4.93 to −2.76)	< 0.001
	Arthritis or rheumatism	−8.29 (−10.6 to −5.99)	< 0.001
	Diabetes	−6.61 (−9.68 to −3.55)	< 0.001
	Psychological distress (K10), per point	−0.89 (−1.05 to −0.73)	< 0.001
Role functioning	Female sex	4.38 (2.53 to 6.24)	< 0.001
	Age: 18–29 v 50–59 years	5.84 (2.29 to 9.39)	0.001
	Self-reported general health, per point	−4.61 (−5.96 to −3.27)	< 0.001
	Arthritis or rheumatism	−7.69 (−10.46 to −4.92)	< 0.001
	Psychological distress (K10), per point	−1.08 (−1.27 to −0.90)	< 0.001
Emotional functioning[2]	Male sex	−3.08 (−4.39 to −1.77)	< 0.001
	Self-reported general health, per point	−1.55 (−2.42 to −0.68)	< 0.001
	Psychological distress (K10), per point	−2.41 (−2.52 to −2.29)	< 0.001
Cognitive functioning	Psychological distress (K10), per point	−1.75 (−1.89 to −1.61)	< 0.001
	Not being married v being married	−4.48 (−6.71 to −2.25)	< 0.001
Social functioning	Female sex	3.41 (1.57 to 5.26)	< 0.001
	Self-reported general health, per point	−3.80 (−5.03 to −2.57)	< 0.001
	Arthritis or rheumatism	−7.88 (−10.6 to −5.11)	< 0.001
	Psychological distress (K10), per point	−1.46 (−1.64 to −1.29)	< 0.001
	Being born outside Australia	−4.27 (−6.75 to −1.80)	0.001
Fatigue	Age: 18–29 v 50–59 years	−4.56 (−7.4 to −1.72)	0.002
	Self-reported general health, per point	6.03 (4.99 to 7.07)	< 0.001
	Arthritis or rheumatism	3.61 (1.55 to 5.67)	< 0.001
	Psychological distress (K10), per point	1.46 (1.33 to 1.59)	< 0.001
Nausea/vomiting	Age: 18–29 v 40–49 years	−4.53 (−6.91 to −2.16)	< 0.001
	Age: 18–29 v 50–59 years	−5.43 (−7.96 to −2.90)	< 0.001
	Age: 18–29 v 60–69 years	−5.74 (−8.15 to −3.32)	< 0.001
	Age: 18–29 v 70 or more years	−4.7 (−7.50 to −1.90)	0.001
	Psychological distress (K10), per point	0.99 (0.84 to 1.14)	< 0.001
Pain	Better self-reported general health	6.09 (4.88 to 7.30)	< 0.001
	Arthritis or rheumatism	17.6 (14.5 to 20.7)	< 0.001
	Psychological distress (K10), per point	1.29 (1.12 to 1.46)	< 0.001
Dyspnoea	Female sex	−3.15 (−5.04 to −1.26)	0.001
	Self-reported general health, per point	3.82 (2.47 to 5.17)	< 0.001
	Diabetes	6.58 (2.85 to 10.3)	0.001
	Psychological distress (K10), per point	0.99 (0.81 to 1.17)	< 0.001
Insomnia	Self-reported general health, per point	4.51 (3.14 to 5.89)	< 0.001
	Arthritis or rheumatism	6.58 (3.19 to 9.97)	< 0.001
	Psychological distress (K10), per point	1.72 (1.54 to 1.91)	< 0.001

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Scale	Characteristic	Unstandardised regression parameter (95% CI)	P
Appetite loss	Age: 18–29 *v* 40–49 years	−6.08 (−9.33 to −2.83)	< 0.001
	Age: 18–29 *v* 50–59 years	−7.02 (−10.6 to −3.41)	< 0.001
	Age: 18–29 *v* 60–69 years	−9.18 (−12.8 to −5.57)	< 0.001
	Age: 18–29 *v* 70 or more years	−8.33 (−12.2 to −4.46)	< 0.001
	Psychological distress (K10), per point	1.12 (0.95 to 1.30)	< 0.001
Constipation	Psychological distress (K10), per point	1.10 (0.92 to 1.29)	< 0.001
Diarrhoea	Arthritis or rheumatism	3.89 (1.50 to 6.28)	< 0.001
	Psychological distress (K10), per point	0.95 (0.78 to 1.12)	< 0.001
Financial difficulties	Stroke	19.8 (9.23 to 30.34)	< 0.001
	Arthritis or rheumatism	4.7 (1.7 to 7.7)	0.002
	Psychological distress (K10), per point	1.43 (1.25 to 1.61)	< 0.001

CI = confidence interval; EORTC = European Organisation for Research and Treatment of Cancer; K10 = Kessler Psychological Distress Scale. ◆

pre-disease or pre-treatment baseline assessments are not available, including survivorship studies, cancer registry studies in which patients are recruited after diagnosis, and surgical trials for which eligibility is determined by a definitive staging biopsy result. Such comparisons may also quantify the extent to which survivors have returned to pre-morbid levels of health.

3 EORTC Quality of Life Questionnaire (QLQ-C30) Australian population reference values: adjusted mean scores* (with standard deviations), by sex

QLQ-C30 scale	Men	Women	Clinical interpretation of difference[§]
Number of respondents	897	924	
Global quality of life[†]	66.9 (21.2)	70.1 (21.7)	Trivial
Physical functioning[†]	86.6 (19.7)	91.7 (18.2)	Small
Role functioning[†]	84.6 (24.5)	92.8 (22.3)	Small
Emotional functioning[†]	83.2 (23.7)	78.7 (24.2)	—
Cognitive functioning[†]	86.7 (22.3)	89.3 (21.6)	Trivial
Social functioning[†]	86.5 (24.9)	94.7 (22.8)	Small
Fatigue[‡]	23.6 (21.6)	24.2 (22.4)	Trivial
Nausea/vomiting[‡]	6.1 (17.4)	3.2 (16.5)	Trivial
Pain[‡]	24.3 (25.7)	19.4 (26.3)	Trivial
Dyspnoea[‡]	14.5 (23.9)	9.0 (22.1)	Small
Insomnia[‡]	25.5 (29.3)	23.2 (30.7)	Trivial
Appetite loss[‡]	9.3 (21.9)	7.9 (21.8)	Trivial
Constipation[‡]	10.0 (22.6)	8.8 (22.7)	Trivial
Diarrhoea[‡]	5.8 (20.8)	6.0 (19.4)	Trivial
Financial difficulties[‡]	9.1 (24.0)	3.3 (23.8)	Small

EORTC = European Organisation for Research and Treatment of Cancer. * Adjusted for age, self-reported general health, psychological distress, country of birth, education, Indigenous status, marital status, comorbid conditions (arthritis/rheumatism, cancer, diabetes, HIV/AIDS, kidney disease). † Higher scores indicate better quality of life or function. ‡ Higher scale scores indicate higher level of problem. § According to the criteria of Cocks and colleagues[22] (not available for "emotional functioning"). ◆

Published general population reference values for the EORTC QLQ-C30 were based predominantly on data for European cohorts.[4–8] The differences between our Australian values and reported EORTC general population values[6] were trivial. This does not mean the Australian values are superfluous, as they are intrinsically more appropriate for interpreting Australian data. For example, the threshold for a small but clinically important difference on the "role functioning" scale is seven points. The EORTC reference value (84.7) is four points lower than our Australian reference value (88.8); a mean score for an Australian sample of 80.0 would therefore be clinically important, but this would not be apparent if compared with the EORTC reference value.

Previous studies have identified differences between test reference values in Australia and those from other countries. In a study of the Rand Corporation medical outcomes short-form 36 (SF-36) health survey, Queensland norms for role limitations caused by physical problems and pain were lower than in the US, while those for physical functioning and mental health were higher;[10] South Australians similarly reported higher SF-36 physical and mental component scores than Americans.[9] Global quality of life generally increased with age in our Australian sample, whereas a Danish study found that it declined.[8] It is unclear whether such differences between countries reflect real differences in the health of their populations or are caused by methodological differences, including how questions or response wording are interpreted and the effects of sampling bias on variables important for self-reported quality of life.

Evidence for associations in Australia between socio-demographic characteristics and patient-reported outcomes is inconsistent. In a normative study of Queensland residents, higher education and being married were respectively associated with greater social wellbeing and functional wellbeing.[23] We found that education did not influence any QLQ-C30 subscale scores, but marital status influenced cognitive functioning and nausea/vomiting scores. In our study, psychological distress levels influenced scores on all 15 QLQ-C30 subscales, and self-reported general health influenced those on nine scales. Women reported better physical, role, and social functioning than men, but lower levels of emotional functioning. Interestingly, younger age was associated with higher levels of fatigue, nausea/vomiting, appetite, pain, and diarrhoea, despite reported general health for these age groups being

4 EORTC Quality of Life Questionnaire Core-30 (QLQ-C30) Australian population reference values: adjusted mean scores* (with standard deviations), by age group

QLQ-C30 scale	Age group (years)						Clinical interpretation of difference§
	18–29	30–39	40–49	50–59	60–69	70 or more	
Number of respondents	402	325	322	296	241	235	
Global quality of life†	66.8 (19.3)	66.2 (21.8)	68.1 (21.7)	69.0 (23.3)	70.8 (21.1)	72.3 (21.6)	Trivial to small
Physical functioning†	88.7 (18.7)	88.8 (20.5)	92.3 (17.6)	90.1 (19.1)	89.4 (16.6)	84.6 (19.9)	Trivial to small
Role functioning†	85.4 (25.0)	87.6 (24.7)	89.8 (24.4)	91.1 (22.3)	91.5 (20.6)	89.2 (21.4)	Trivial
Emotional functioning†	81.9 (24.8)	80.4 (25.7)	79.0 (25.5)	80.0 (24.0)	82.0 (17.7)	82.8 (17.8)	—
Cognitive functioning†	87.4 (25.5)	87.9 (23.9)	87.3 (23.3)	88.1 (21.3)	88.0 (15.8)	90.2 (12.6)	Trivial to medium
Social functioning†	90.0 (23.6)	89.5 (25.4)	89.7 (26.3)	89.4 (25.1)	94.5 (19.5)	92.8 (20.2)	Trivial to small
Fatigue‡	25.9 (21.7)	25.6 (23.8)	24.1 (23.0)	21.3 (23.3)	21.6 (19.2)	23.5 (18.1)	Trivial to small
Nausea/vomiting‡	7.6 (22.0)	7.7 (22.9)	3.1 (13.3)	2.2 (11.2)	1.9 (7.3)	3.0 (7.7)	Trivial
Pain‡	23.1 (23.4)	21.3 (24.8)	21.7 (27.0)	21.9 (28.1)	21.1 (26.0)	20.8 (27.7)	Trivial
Dyspnoea‡	13.9 (24.3)	14.4 (25.2)	9.5 (21.5)	8.9 (23.5)	10.4 (18.9)	12.2 (22.2)	Trivial to small
Insomnia‡	25.2 (30.7)	23.6 (30.8)	25.6 (32.9)	25.1 (30.1)	24.9 (28.0)	20.7 (24.4)	Trivial to small
Appetite loss‡	13.2 (25.9)	12.8 (25.3)	7.0 (19.9)	6.1 (20.1)	4.0 (14.0)	4.9 (15.0)	Trivial to small
Constipation‡	11.3 (25.7)	11.1 (25.7)	7.9 (20.1)	8.1 (21.2)	6.5 (18.2)	10.3 (19.3)	Trivial
Diarrhoea‡	8.6 (25.7)	8.0 (24.2)	6.0 (18.3)	2.5 (13.6)	4.4 (13.9)	3.8 (12.8)	Trivial to small
Financial difficulties‡	5.4 (24.1)	8.4 (27.8)	6.8 (25.3)	7.3 (25.9)	3.8 (16.4)	4.3 (17.1)	Trivial to small

EORTC = European Organisation for Research and Treatment of Cancer. * Adjusted for age, self-reported general health, psychological distress, country of birth, education, Indigenous status, marital status, comorbid conditions (arthritis/rheumatism, cancer, diabetes, HIV/AIDS, kidney disease). † Higher scores indicate better quality of life or function. ‡ Higher scale scores indicate higher level of problem. § According to the criteria of Cocks and colleagues[22] (not available for "emotional functioning"). ◆

similar to population reference values (unadjusted data).[16] These symptoms may reflect poor health behaviours, such as binge drinking or poor diet, but further investigation is needed. That pain values were higher for adults under 40 than for those over 40 years of age was surprising, and was perhaps attributable to the higher levels of distress among younger people in our sample. Arthritis was associated with poorer quality of life on nine of the 15 QLQ-C30 domains. The International Quality of Life Assessment Project similarly found arthritis was more closely related to quality of life in the general population than any other chronic condition.[24] These findings highlight the importance of the socio-demographic characteristics and comorbid conditions of people in clinical samples when reporting quality of life.

Strengths and limitations

Our study included a large sample that was representative of the general Australian population by age and sex, and we assessed a range of socio-demographic variables in a manner that allowed comparison with population reference data. We assessed associations between these socio-demographic variables and QLQ-C30 subscale scores and adjusted mean QLQ-C30 scores with the resultant coefficients, and presented our results by age and sex. We administered and scored the questionnaire in accordance with EORTC guidelines,[2] enabling future comparisons with QLQ-C30 data derived from clinical data.

Obtaining a sample that is representative for all demographic variables is difficult, as is determining a priori which variables are the most important predictors of outcomes. Age and sex were selected for quota sampling because they are important predictors of self-reported health.[5] We identified Australian reference datasets for key demographic characteristics and measured

them in our sample with the same methods so that we could identify and adjust our data for any non-representativeness.

Our sample included a small proportion of people (9.5%) with a personal history of cancer. As it is estimated that 50% of Australians will be diagnosed with a neoplasm before the age of 85 and cancer-related mortality rates are falling,[19] more Australians than ever are living with the long term effects of cancer. It is consequently important that people with cancer and other chronic conditions were represented in our sample. We did not collect data on geographic location, income, migrant status, or disability, so we could not assess the representativeness of our sample for these features. Data on chronic conditions were self-reported and not verified in other sources.

Investigators using health surveys are moving from face-to-face, postal, and telephone-based approaches to web-based methods that are more cost-effective and convenient for researchers. The appropriateness of online panels for research has been discussed.[25,26] Frequent survey participation can affect data quality, as experienced panellists may be more likely to provide truthful answers because of greater trust in the survey process.[25] Further, education and internet access were positively correlated in one study, but online panel membership and education were negatively correlated.[26] The mean education level of our panel was higher than for the HILDA survey participants,[16] but education level did not influence scores on any QLQ-C30 scales.

Our participants reported higher psychological distress levels than the 2007 Australian K10 reference values,[15] particularly in younger age groups, consistent with the findings of a study of internet panel control participants.[27] As we found that psychological distress was associated with less positive scores on all QLQ-C30 scales, the possibility of an insidious selection bias in

5 EORTC Quality of Life Questionnaire (QLQ-C30) Australian population reference values: adjusted mean scores* (with standard deviations) and EORTC general population values[6]

	Total Australian sample	EORTC general population reference value	Clinical interpretation of difference
Number of respondents	1821	7802	
Global quality of life[†]	68.5 (21.5)	71.2 (22.4)	Trivial
Physical functioning[†]	89.2 (19.0)	89.8 (16.2)	Trivial
Role functioning[†]	88.8 (23.4)	84.7 (25.4)	Trivial
Emotional functioning[†]	80.9 (24.1)	76.3 (22.8)	—
Cognitive functioning[†]	88.0 (21.9)	86.1 (20.0)	Trivial
Social functioning[†]	90.7 (23.9)	87.5 (22.9)	Trivial
Fatigue[‡]	23.9 (22.0)	24.1 (24.0)	Trivial
Nausea/vomiting[‡]	4.6 (17.0)	3.7 (11.7)	Trivial
Pain[‡]	21.8 (26.0)	20.9 (27.6)	Trivial
Dyspnoea[‡]	11.7 (23.0)	11.8 (22.8)	Trivial
Insomnia[‡]	24.4 (30.0)	21.8 (29.7)	Trivial
Appetite loss[‡]	8.6 (21.9)	6.7 (18.3)	Trivial
Constipation[‡]	9.4 (22.6)	6.7 (18.4)	Trivial
Diarrhoea[‡]	5.9 (20.1)	7.0 (18.0)	Trivial
Financial difficulties[‡]	6.2 (23.9)	9.5 (23.3)	Trivial

EORTC = European Organisation for Research and Treatment of Cancer. * Adjusted for age, self-reported general health, psychological distress, country of birth, education, Indigenous status, marital status, comorbid conditions (arthritis/rheumatism, cancer, diabetes, HIV/AIDS, kidney disease). † Higher scores indicate better quality of life or function. ‡ Higher scale scores indicate higher level of problem. § According to the criteria of Cocks and colleagues[22] (not available for "emotional functioning"). ◆

online panels warrants investigation. Other possible explanations include general or generational increases in psychological distress over time (in our case, between 2007 and 2015–2016; for the earlier study, between 1995 and 2011[27]).

The differences may also indicate different response biases in normative surveys. While the K10 reference data[15] were based on responses from 8841 people, the response rate was only 60% and the data were collected in face-to-face interviews; similarly, the response rate for the HILDA-10 survey was only 66%.[16] These reference data are the best available, but all sampling methods are prone to selection bias, a risk that increases as the response rate falls. Other population survey sampling approaches, such as random digit dialling, probability sampling, and electoral roll sampling, also achieve relatively low response rates (range, 46–71%).[4,28,29] Our quota sampling approach precluded calculation of a response rate, but the survey completion rate (92%) was excellent.

Conclusion

We have reported the first QLQ-C30 general population reference values specific to Australia. These values will assist interpretation of QLQ-C30 scale scores for Australian patients with cancer, both in existing data and data generated by future studies. They will be particularly useful for intervention studies without baseline data, studies in which patients are symptomatic at baseline, and for cross-sectional and survivorship studies. Our findings also show that it is important to present socio-demographic data together with patient-reported outcome data, and to know which characteristics influence patient-reported outcomes.

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Supporting Information

Additional Supporting Information is included with the online version of this article.