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Development and validation of a parent-proxy health-related quality of life survey for Australian First Nations children

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ABSTRACT

Objective Within Australia, Aboriginal and Torres Strait Islander (First Nations) populations perceive health and well-being differently to non-Indigenous Australians. Existing health-related quality of life (HR-QoL) measurement tools do not account for these differences. The objective of this study was to develop and validate a culturally specific parent-proxy HR-QoL measurement tool for First Nations children.

Design Scale development was informed by parents/carers of children with a chronic illness and an expert panel. The preliminary 39-item survey was reviewed (n=12) and tested (n=163) with parents/carers of First Nations children aged 0–12 years at baseline with comparative scales: the Kessler Psychological Distress Scale, generic HR-QoL (Paediatric QoL Inventory 4.0, PedsQL$^{4.0}$) and Spence Children's Anxiety Scale, and repeated (n=46) 4 weeks later. Exploratory Factor Analysis was used for scale reduction. Reliability and validity were assessed by internal consistency, test–retest, and correlations with comparison scales.

Results Items within our First Nations-Child Quality of Life (FirstNations-CQoL) were internally consistent with Cronbach's alpha coefficients of ≥0.7 (quality of life, 0.808; patient experience, 0.880; patient support, 0.768) and overall test–retest reliability was good (r=0.75; 95% CI 0.593 to 0.856). Convergent validity was observed with the PedsQL$^{4.0}$ with Pearson's coefficients of r=0.681 (ages 2–4 years); r=0.651 (ages 5–12 years) and with the Kessler Psychological Distress scale (r=−0.513). Divergent validity against the Spence Anxiety Scale was not demonstrated.

Conclusions The FirstNations-CQoL scale was accepted by the participants, reliable and demonstrated convergent validity with comparison measures. This tool requires further evaluation to determine responsiveness, its minimal important difference and clinical utility.

INTRODUCTION

Improved health-related quality of life (HR-QoL) is considered a desirable patient outcome in addition to standard biomedical outcomes. Evaluated using a psychometric tool, measuring HR-QoL can provide health

Strengths and limitations of this study

► To the best of our knowledge, this study is the first to develop a culturally specific health-related quality of life metric for First Nations Australian people.

► The study's strengths include the consultative approach taken to develop and refine the concepts included in the measurement tool, and the inclusion of infants and children with different health conditions.

► The study is limited by the availability of validated psychometrics for First Nations Australian people; we were unable to determine divergent validity.

► The FirstNations-Child Quality of Life would benefit from further evaluation using other metrics, a disease-specific sample and treatment context.

professionals valuable insight into a patient's subjective health status. However, one measure does not fit all. HR-QoL is informed by culture and value systems and measures should be reflective of the population they are used with.[1]

Within Australia, the way Aboriginal and Torres Strait Islander (hereafter respectfully referred to as First Nations) populations perceive health and well-being is different to other Australians.[2 3] Unlike Anglo-centric notions of health, the well-being of First Nations Australians is not an individual concept, but can be better understood in how the individual is connected to their identity, culture, spirituality, family, community and country.[4] Social and historical determinants such as colonisation also play a role in how health and well-being is perceived. The colonial process has undermined the autonomy, empowerment and recognition of First Nations people and as such, experiences of health and healthcare are valued differently to those that have not experienced the same marginalisation.[2 3]

Angell *et al*'s review of available HR-QoL measures for Indigenous populations globally concluded that available tools are primarily built using Anglo-centric notions of health. As these do not adequately capture the subjective HR-QoL of Indigenous populations (including First Nations Australians), psychometric tools should be developed in cooperation with First Nations Australians in order to accurately reflect their values.[2–6] To the best of our knowledge, there are no tools that have been developed or validated specifically to measure the HR-QoL of Australian First Nations adults or children.[3]

This study was informed by a prior qualitative investigation which aimed to understand the meaning of HR-QoL to parents and carers of Australian First Nations children with a chronic illness. The qualitative findings have been published.[7] Older children are able to report their own HR-QoL but a parent-proxy report is required for young or unwell children who are unable to report for themselves.[8] Understanding the parent or carer's perspectives can also provide insight into healthcare utilisation and family values regarding potential treatment options.[8]

In the absence of a validated HR-QoL tool for First Nations children, we developed and validated a culturally specific parent-proxy HR-QoL measurement tool for First Nations children. The First Nations-Child Quality of Life (FirstNations-CQoL) aims to reflect the values associated with the HR-QoL of First Nations Australian children from the perspective of their parents and carers. Here, we describe the procedure we used to identify items, draft the tool and test its validity.

METHOD
Study design
Development of our measurement tool, the First Nations-CQoL, consisted of three stages: (A) development of a draft tool based on the findings of the qualitative study,[7] (B) gathering and integrating feedback, and (C) validation of the tool using statistical techniques and comparative measures.

Patient and public involvement
The impetus for this study came from clinician-led awareness in using Western-culture-based HR-QoL for First Nations peoples. This was discussed with the First Nations Reference Group based in Darwin approximately 7 years ago. When specific funding then became available, the pursuit and facilitation of the study was endorsed by several First Nations leaders who had engaged with Prof Anne Chang in her work treating respiratory illnesses experienced by First Nations children. Both clinicians and patient families realised that the available HR-QoL measures had not been created with First Nations people and thus a novel approach was needed to capture First Nations perspectives. This study was informed by a qualitative study with First Nations parents which explored how HR-QoL should and could be measured. Additional consultation with participants was also sought in

the development of the tool during stage B (gathering and integrating feedback), to ensure that participants had a say in the data collection process (with respect to which questions should be asked and the time required to participate), as well as the final product. Participants were not involved in the plans to disseminate the findings but made aware during the consent process that the findings of the study would be published in a scientific journal and presented in relevant community settings and conferences. Participants were also invited to contact the researchers if they had any questions about the study or the findings.

Setting and participants
The primary recruitment location was the Queensland Children's Hospital in Brisbane, Australia, the State's only tertiary paediatric facility. Recruitment took place across the hospital, on patient wards and in outpatient clinics. Additional recruitment took place in regional areas outside of Brisbane at primary healthcare clinics located in Toowoomba and Warwick; these centres are approximately 2 hours drive west of Brisbane.

Parents and carers of First Nations children aged 0–12 years inclusive were eligible to participate. Stage B (gathering and integrating feedback) included only parents and carers of children with a chronic health condition and recruitment was ceased for this stage once no further new feedback was obtained. Stage C (validation) included parents and carers of children with and without chronic conditions. Children were excluded if they were in the care of State services, as primary parents/carers would be unable to consent and we would be unable to determine whether the state service could be an adequate proxy for the child.

Screening of potential participants for stages B and C was supported by two hospital Indigenous Liaison officers who provided daily guidance on which families were available to approach for recruitment. The primary researcher (KB) and another research assistant approached potential participants in person in the hospital clinic waiting rooms and on the hospital wards. Participants in Toowoomba and Warwick were recruited from the clinic waiting room. The study protocol was explained verbally and through a written plain language statement and signed consent was obtained from all potential participants.

During stage B, potential participants were invited to complete the draft paper-based survey which included demographic and health-related questions about themselves and their children, as well as the associated comparison measures. The survey had additional blank space for written feedback and participants were able to provide verbal feedback to the primary researcher (KB).

For stage C, participants had the option of completing the finalised paper-based survey or a deidentified online survey (via surveymonkey.com.au). For the paper-based survey, participants were required to consent at the time of recruitment as to whether they would agree to being contacted 4 weeks later to complete the scales again. For

the online survey, participants were able to indicate after completing the survey online whether they consented to the follow-up survey being sent 4 weeks later. For both stages B and C, assistance with understanding and/or reading the survey was offered to all participants at the time of consent. The researcher explained that participants could ask questions or receive assistance in reading and completing the material if that was their preference.

Stage A: development of draft FirstNations-CQoL
Item development
Fifty-two items for the FirstNations-CQoL were obtained from our prior qualitative study that involved yarning sessions with 26 First Nations parents and carers of children aged less than 18 years who experienced a chronic condition.[7] This first study explored how parents and carers perceived the concept of HR-QoL as it related to their children. Thematic analysis of the qualitative data was completed by two researchers (KB and MT), and themes derived to inform potential items on the HR-QoL tool. An 'item' refers to the concept that is used to represent the different facets of HR-QoL in the form of a question when placed into survey format.

Item reduction
The 52 items above were formatted in a document with a ranking scale to determine an item Content Validity Index (I-CVI) by an expert panel. We used Polit and Beck's method where each item could be ranked from 1 (do not use) to 4 (definitely Keep).[9] Six experts independently ranked these items in accordance with Polit and Beck's method.[9] These included First Nations academics, First Nations Health Workers and clinicians who work closely with First Nations Australian paediatric and adult populations. The ranking was not purposefully blinded, yet experts worked independently in their decision making. The I-CVI score was determined by summing the percentage of agreement between the panel: items were included on greater than 79% agreement and removed if less than 69% agreement, those in-between were iteratively reviewed until a resolution was achieved.[9] The ranking process effectively reduced the number of items from 52 to 39 items and these were formatted into questions in a paper-based survey format with a five-point Likert-style scale for answers (never, almost never, sometimes, often, always).

Materials
The 39-item FirstNations-CQoL was then formatted and collated with the following questionnaires (the comparative scales) for stage B, before being finalised and formatted into an additional online version for stage C.
1. Single item HR-QoL. Participants were invited to indicate on a numerical scale from 1 (terrible) to 10 (excellent), how they would rate their child's HR-QoL.
2. The Kessler Psychological Distress Scale (KPDS).[10] This is a validated 10-item scale investigating whether a person has been experiencing anxiety or depression in the past 4 weeks. The tool has been used with general Australian adults previously, and adapted versions of the scale (the Kessler 5 and 6) validated with Australian First Nations adults.[5] Participants were invited to complete the Kessler 10 based on their own experiences as adults. The measure assesses parent well-being at the time of completion.
3. The Paediatric QoL Inventory 4.0 (PedsQL[4.0]).[11] This is a validated 23-item parent-proxy measure of child HR-QoL. It has a five-point Likert-style scale (0=never a problem to 4=almost always a problem). The PedsQL[4.0] inventory has demonstrated reliability and validity and is reported to be applicable across a variety of settings, including clinical trials and research.[11] The inventory caters to four age groups (2–4, 5–7, 8–12 and 13–18 years). Depending on the age of their child, parents of children aged 2–12 were invited to complete the respective measure.
4. The Spence Children's Anxiety Scale, parent version.[12] This is a scale designed to measure anxiety in children. There are two versions of the scale, one for preschool children and one for school-aged children. The preschool scale consists of 28 items that ask parents to report on the frequency of which an item is true for their child. Each item is rated on a five-point scale from 0 'not at all' to 4 'very often true'. The scale has been validated for Australian children aged 2.5–6 years.[13] The school-aged version consists of 44 items and has been validated for Australian children aged 6–18 years. The parent rates on a four-point scale (never, sometimes, often or always) how often each of the items happens to their child.[13]

In addition to the above, sociodemographic, cultural, health and well-being information were collected by self-report.

Stage B: gathering and integrating feedback
The draft 39-item FirstNations-CQoL and related materials were disseminated to 12 participants (participants included mothers who identified as First Nations women and whose children had a chronic illness) to enquire about the appropriateness and acceptability of the tool. Participants were encouraged to provide both verbal and written feedback on the usability and applicability of the tool to First Nations HR-QoL values. Feedback on the item content specifically was encouraged, including whether items should be deleted, created, or refined. As well, feedback on the entirety of the research materials was sought.

All 12 participants who undertook the pilot study indicated that they thought that the FirstNations-CQoL was both acceptable and appropriate for use with Australian First Nations families. While we received feedback to shorten the tool if possible, the participants indicated that this was not a priority for stage (C) validation as all the content was relevant and no items were deemed inappropriate or unacceptable. We thus retained all 39 items chosen from the item reduction process.

Stage C: statistical validation of FirstNations-CQoL

Stage C comprised the dissemination of the tool along with the comparison measures above to participants recruited through the Queensland Children's Hospital and community clinics as described above.

Sample size

Guidelines for establishing the respondent-to-item ratio vary, 5:1 (participants: question) is suggested as the minimum.[14] We aimed for a ratio of 6:1. We had initially anticipated no more than 21 questions to be included on the FirstNations-CQoL and as such aimed to recruit 160 participants (allowing for 20% attrition over a 4-week test–retest period) with respect to our timelines.

Identification of domains

Participant feedback and prior research[15] have indicated a preference for measures that are shorter and quicker to complete. In this instance there was also an insufficient participant to item ratio to complete an exploratory factor analysis (EFA) with all 39 items. An EFA is a statistical technique that is used to summarise variables that have patterned correlations, known as latent factors.[16] For HR-QoL scales, this means evaluating whether the themes that have been identified as relating to HR-QoL conceptually, also correlate together statistically into factors or what is commonly termed 'domains'. This technique is best performed with a large respondent-to-item ratio.[16] Thus, it was decided to reduce items prior to conducting the EFA. Item reduction was informed by item correlation, by the qualitative data collected during item creation, and professional decision making; the items which were considered to be most representative of the concept were retained. To facilitate the EFA, principal axis factoring was used for extraction with Promax rotation used to account for correlation among factors.[17] The number of factors included were chosen with consideration of the proportion of variance explained by each factor, viz: number of eigenvalues greater than one and clinical interpretation of factors. Once the factors were determined, they were reviewed by First Nations health professionals (n=5) who independently evaluated the relevance and applicability of the factors as domains of child HR-QoL.

Reliability and validity

Cronbach's alpha was used to examine internal consistency and intraclass correlation (ICC) was used to assess test–retest reliability when the survey was repeated by participants 4 weeks later. Internal scale reliability refers to the correlation of the items within the scale.[18]

To evaluate construct validity, Pearson's correlation was used to examine the correlations between the FirstNations-CQoL domains and comparative measures. Construct validity refers to how a survey correlates to other surveys with similar (convergent) and dissimilar (divergent) constructs.[18] For instance, we would expect the FirstNations-CQoL to be moderately correlated to the

established Paediatric QoL Inventory 4.0 (PedsQL$^{4.0}$) and weakly correlated to the Spence Anxiety scale. Pearson coefficients of 0.7 were considered strong, 0.4–0.6 moderate and ≤0.3 weak.[19] Data were analysed using SPSS (SPSS Statistics for Windows, V.25.0, IBM) and R (R Core Team, V.3.6.3, www.r-project.org).

Descriptive statistics were produced for all demographic characteristics and are presented using means and SD for data that were normally distributed and medians and IQR for non-parametric data. Missing data in the scales were imputed using the expectation-maximisation algorithm to preserve relationships between variables.[20]

RESULTS

Baseline characteristics

Of the 335 potential participants screened, 263 were enrolled. Of these, 3 withdrew (due to other commitments) and 97 did not return the survey (lost to follow-up), leaving 163 who completed the baseline survey. Of the 163, 46 repeated the survey 4 weeks later. The demographic characteristics of the parent/carer and child are presented in table 1. The majority (87.1%) of participants were female and mothers (79.7%) to the child for whom they were completing the survey; the median age of the children was 5.7 years, IQR 6.9.

Identification of domains

Twenty-one items were analysed using EFA resulting in five factors with eigenvalues greater than one explaining 63% of the total variance. However, models containing the four and five factor solutions did not converge, indicating a simpler three factor model was more appropriate, explaining 52% of the variation. The three latent factors reflected themes raised during item creation: quality of life, patient experience and patient support (table 2). The subscale correlations were weak to moderate: quality of life and patient experience (r=0.359, p<0.001); quality of life and patient support (r=0.406, p<0.001) and patient support and patient experience (r=0.433, p<0.001), indicating low overlap between factors. There was a consensus from the panel of First Nations health professionals that these domains were representative of child HR-QoL.

Reliability

The novel HR-QoL tool demonstrated good internal consistency, with Cronbach's alpha coefficients of ≥0.7 (Cronbach's alpha for quality of life=0.808; patient experience=0.880; patient support=0.768). Test–retest reliability was conducted with 45 participants. Good reliability was observed for the overall scale (ICC r=0.753; 95% CI: 0.593 to 0.856) and subscale reliability varied: quality of life (ICC r=0.663; 95% CI:0.462 to 0.799), patient experience (ICC r=0.744, 95% CI:0.579 to 0.850) and patient support (ICC r=0.794; 95% CI:0.655 to 0.881) are displayed in table 3.

Validity

The FirstNations-CQoL was moderately to strongly correlated to the PedsQL$^{4.0}$, with Pearson's coefficients

Table 1 Characteristics of participants at baseline and at 4-week follow-up

Characteristics	N=163 (%)	N=46 (%)
Gender of children		
Male	101 (61.9)	30 (65.2)
Female	61 (37.4)	16 (34.8)
Missing	1 (0.6)	0
Age range of children		
Less than 24 months	34 (21.1)	11 (23.9)
2–4 years	38 (23.6)	11 (23.9)
5–7 years	32 (19.8)	7 (15.2)
8–12 years	57 (35.4)	17 (37.0)
Missing	2 (1.2)	0
Gender of parents/carers		
Male	21 (12.8)	5 (10.9)
Female	142 (87.1)	41 (89.1)
Age range of parents/carers		
18–25 years	23 (14.1)	5 (10.9)
26–35 years	66 (40.4)	17 (37.0)
36–45 years	46 (28.2)	17 (37.0)
46+ years	24 (14.7)	7 (15.1)
Missing	4 (2.4)	0
Relationship to child		
Father	17 (10.4)	3 (6.5)
Mother	130 (79.7)	38 (82.6)
Relative/carer	16 (9.8)	5 (10.9)
Care type at home		
Both parents	87 (53.3)	26 (56.5)
Single parent	46 (28.2)	12 (26.1)
Shared care/relative/carer	18 (11.0)	6 (13.0)
Missing	12 (7.3)	2 (4.4)
Employment status		
Full time	41 (25.1)	14 (30.4)
Part time	25 (15.3)	8 (17.4)
Casual	11 (6.7)	5 (10.9)
Not in paid employment	84 (51.5)	91 (41.3)
Missing	2 (1.2)	0
Home location		
Major city	108 (66.2)	38 (82.6)
Inner regional	36 (22.0)	4 (8.7)
Outer regional/rural/remote	17 (10.4)	4 (8.7)
Missing	2 (1.2)	0
Indigenous status of parent/carer		
Aboriginal	83 (50.9)	22 (47.8)
Torres Strait Islander	8 (4.9)	2 (4.3)
Both	9 (5.5)	2 (4.3)
Non-Indigenous	53 (32.5)	19 (41.3)
Declined	7 (4.2)	1 (2.2)
Missing	3 (1.8)	0

of r=0.681 for ages 2–4 years and r=0.651 for ages 5–12 years. Likewise, the KPDS (r=−0.513) and independent assessment of HR-QoL (single-item scale) by parents was moderately correlated (r=0.480) to the FirstNations-CQoL, suggesting acceptable convergent validity across the relative comparison measures. Divergent validity was not demonstrated against the Spence Anxiety Scales, the FirstNations-CQoL being moderately correlated to both the preschool (r=−0.466) and school age (r=−0.535) scales, presented in table 4.

DISCUSSION

As far as we are aware, we have developed the first parent-proxy HR-QoL tool applicable to Australian First Nations children for use in clinical and research settings. In testing with 163 parents/carers of First Nations children in South-East Queensland, the tool demonstrated reliability (internal consistency, test–retest) and validity (convergent) for use with parents of First Nations children demographically similar to our study population.

We identified three domains and 21 questions (items) that reflected concepts of quality of life, patient experience and patient support. These domains were determined by evaluating which items correlated together via EFA and whether these groupings were logical and appropriate in terms of content from the perspective of First Nations health professionals. The domains of the FirstNations-CQoL are not typical domains of current Western-based HR-QoL, such as found in well-established proxy measures: PedsQL[4.0],[11] KINDL[R21] and the Child Health Questionnaire.[22] In these established HR-QoL measures, the domains reflect individual functioning as it relates to physical, mental and social well-being.[23] For example, the widely used PedsQL[4.0] has four domains: (1) physical functioning, (2) emotional functioning, (3) social functioning and (4) school functioning.[11] The items included in these domains query the functioning of the individual, that is, 'In the past month, how much of a problem has your child had bathing'.[11] The FirstNations-CQoL also includes items related to individual functioning in the quality of life domain, however it differs to the PedsQL[4.0] and others mentioned, in that it also considers the wider health environment that influences and can facilitate human function, such as a person's interactions with the health system (patient experience domain) and/or whether they have support (patient support domain).

In the patient experience domain, the questions relate to the respondent's perceptions of health information, the delivery of that information and whether respondents feel they have adequate information. Although feeling informed and knowledgeable about one's health is valued generally, it is perhaps more important for First Nations people in terms of HR-QoL.[24] This is because the colonial process has undermined First Nations people's autonomy and access to culturally relevant and safe healthcare.[2] Qualitative studies[7 25–29] demonstrate that First Nation's

Table 2 Results of exploratory factor analysis: item means with SD and factor loadings

Items	Mean (SD)	Patient experience	QOL	Patient support
Felt respected by medical staff	3.08 (0.87)	**0.811**	−0.134	0.000
Felt like you had enough information	2.97 (0.95)	**0.774**	0.093	−0.083
Felt like your child's health situations were well explained	3.14 (0.90)	**0.771**	−0.020	0.045
The medical staff listen to you	2.94 (0.91)	**0.749**	0.064	−0.086
Felt like medical staff are there to help you	3.12 (0.88)	**0.673**	−0.116	0.193
The medical staff don't believe you	2.96 (1.05)	**0.656**	0.028	−0.019
Felt frustrated	2.02 (1.06)	**0.567**	0.197	−0.240
You could ask medical staff questions if you needed to	3.45 (0.81)	**0.547**	−0.031	0.197
You could teach your family about your child's health needs	3.41 (0.85)	**0.446**	0.044	0.219
You have enough knowledge to care for your child when they are sick	3.51 (0.76)	**0.352**	−0.007	0.076
Spend time with family as usual	3.20 (0.97)	0.018	**0.838**	−0.048
Do activities they enjoy	3.03 (0.95)	0.052	**0.765**	−0.024
Felt strong/good/deadly	2.89 (1.00)	−0.043	**0.687**	0.208
Go to school/day care	2.89 (1.27)	0.013	**0.579**	−0.089
Had very little energy	2.49 (1.19)	0.087	**0.535**	−0.141
Slept through the night	2.76 (1.32)	−0.089	**0.485**	0.231
Eating as normal	2.86 (1.16)	−0.108	**0.459**	0.196
Been extra clingy	1.99 (1.12)	0.058	**0.329**	0.007
There is someone you can trust to provide childcare if you are away	3.00 (1.18)	0.026	−0.043	**0.763**
Your family could manage your child's health if they needed to	2.84 (1.14)	−0.046	0.060	**0.716**
You could call someone if you are struggling	3.24 (1.00)	0.189	0.042	**0.592**

Extraction method: principal axis factoring. Rotation Method: promax with Kaiser normalisation.
a. Rotation converged in five iterations.
QOL, quality of life.

parents and carers experience considerable barriers to health literacy and self-efficacy in engaging with the health system to manage child illness which has implications for healthcare utilisation and parent and child wellbeing. Baba et al's work with Aboriginal Medical Services highlights how insufficient information and inadequate support from mainstream health services can leave First Nations patients feeling scared, confused and alone.[30] These experiences are likely to inform child HR-QoL as parents act on their behalf in navigating the health system.

Similarly, in the patient support domain, the questions relate to whether the respondent feels supported in their home environment. It is well established that family and community play a central role in how First Nations people define health and well-being.[2] Yet many social factors can affect the capacity of traditional family support networks,[30] which in turn affects how families are able to cope with child health challenges.[30–34] The relevance of these domains with respect to HR-QoL has been identified, both in our own qualitative investigations,[7] and prior studies investigating how Australian First Nations people

perceive health and well-being.[2 5 25] Moreover, 'having a support network' and 'experience of health services' are recognised components of quality of life as determined by the WHO's Quality of Life Instrument (WHO-QOL) manual.[32] A content evaluation[33] of available HR-QoL measures against the WHO-QOL criteria suggests that many tools were created prior to establishing the differences between individual function and HR-QoL and as such do not adequately reflect HR-QoL in its holistic definition. Acceptance of the First Nations-CQoL at face value by parents and health professionals, and demonstrated convergent validity with the comparison measures, suggest that the incorporation of these domains into future culturally-specific HR-QoL measures is important and worthwhile.

This study provides insight into culturally specific psychometrics for First Nations Australians. An HR-QoL tool, such as the FirstNations-CQoL could be utilised in primary and hospital health settings to inform patient experience and treatment efficacy (in the context of improving HR-QoL). These types of measures are typically quick to complete, can be facilitated using a paper and pen or electronically

Table 3 Internal reliability and test–retest reliability of FirstNations-CQoL scale and scale domains against comparison measures: single-item HR-QoL, KPDS, PedsQL[4.0] and SCAS-P

Measures	Baseline scores				4-week follow-up				Test–retest
	N	Mean	SD	Cronbach's alpha	N	Mean	SD	Cronbach's alpha	ICC
FirstNations-CQoL Total (21-items)	152	61.81	11.72	0.880	45	64.49	11.39	0.876	0.753
FirstNations-CQoL Quality of Life	152	22.12	5.91	0.808	45	23.39	5.60	0.818	0.663
FirstNations-CQoL Patient Experience	152	30.61	6.31	0.880	45	31.68	6.68	0.873	0.744
FirstNations-CQoL Patient Support	152	9.08	2.75	0.768	45	9.42	2.52	0.766	0.794
Single item HR-QoL*	157	7.61	2.13	NA	45	8.13	1.89	NA	0.545
Kessler Scale	161	19.86	8.09	0.937	45	19.11	7.40	0.929	0.812
PedsQL aged 5–12	83	57.74	20.15	0.931	23	62.15	16.43	0.899	0.798
PedsQL aged 2–4	36	75.33	18.12	0.919	23	76.06	16.57	0.897	0.938
Spence preschool	36	20.96	12.74	0.845	11	18.82	14.09	0.881	0.897
Spence school aged	74	25.18	18.24	0.947	23	23.33	13.99	0.908	0.806

*Parent rating of child HR-QoL using single numerical scale
FirstNations-CQoL, First Nations-Child Quality of Life; HRQoL, health-related quality of life; KPDS, Kessler Psychological Distress Scale; NA, not available; PedsQL[4.0], Paediatric QoL Inventory 4.0.

and provide insight into subjective experiences that are challenging to quantify. A strength of the study has been the consultative approach taken to develop the tool; item development was informed by First Nations people's conceptualisations of HR-QoL and subsequently checked for acceptability by a wider population. The findings contribute to the growing understanding of what Australian First Nations families value in terms of HR-QoL and how those values can be evaluated in a health setting. Yet, the project is not without limitations. Demographic information

on those who enrolled but did not complete the survey was unavailable. Thus, we are unable to comment on what factors (eg, socio-economic status) may have influenced participation. Demographic information for those who did participate is varied; as is the demographic information for those who participated in the follow-up survey with the exception of 'location', with more participants from a major city completing the follow-up. This is unsurprising given the impact of travel to the hospital on family time and capacity. Additionally, while participants were offered assistance

Table 4 Construct validity of FirstNations-CQoL against comparison measures: single-item HR-QoL, PedsQL[4.0] ages 2–4 years, PedsQL[4.0] ages 5–12 years, KPDS and SCAS-P

Pearson's correlation	FirstNations-CQoL Total	Single-item HR-QoL	PedsQL aged 5–12	PedsQL aged 2–4	Kessler scale	Spence school age	Spence preschool
FirstNations-CQoL Total	1	0.480*	0.651*	0.681*	–0.513*	–0.535*	–0.466*
Single-item HR-QoL	0.480*	1	0.392*	0.518*	–0.389*	–0.304*	–0.264
PedsQL aged 5–12	0.651*	0.392*	1	.b	–0.498*	–0.707*	.b
PedsQL aged 2–4	0.681*	0.518*	.b	1	–0.385†	.b	–0.548*
Kessler Scale	–0.513*	–0.389*	–0.498*	–0.385†	1	0.492*	0.275
Spence Pre-school	–0.466*	–0.264	.b	–0.548*	0.275	.b	1
Spence School-age	–0.535*	–0.304*	–0.707*	.b	0.492*	1	.b

b. Cannot be computed because at least one of the variables is constant.
*Correlation is significant at the 0.01 level (two tailed).
†Correlation is significant at the 0.05 level (two tailed).
FirstNations-CQoL, First Nations-Child Quality of Life; HRQoL, health-related quality of life; KPDS, Kessler Psychological Distress Scale; PedsQL[4.0], Paediatric QoL Inventory 4.0; SCAS, Spence Children's Anxiety Scale.

to complete the survey if they required it, we are unable to comment on whether literacy levels would have been a deterrent to participation as the vast majority of participants were able to complete the survey without assistance and did not indicate literacy as a barrier. In removing excess items prior to the EFA, it is possible that the results are biased to the researchers. However, the alignment of the resulting domains with the preceding qualitative investigation suggest that the relevant constructs have been adequately represented. Second, given there are no age-appropriate comparison scales for infants age 0–2 years, we combined the infants with children aged 2–4 for comparison to the other measures. While this approach has shown sound psychometric properties in our study, we are unable to distinguish the sensitivity for babies in particular. Likewise, we have been unable to demonstrate divergent validity to the Spence Anxiety Scale. This is likely because several items within the FirstNations-CQoL relate to anxiety. Future research should consider other comparison measures. However, cultural and age appropriate proxy measures for comparison remain limited and there is a dearth of psychometric tools validated for First Nations Australians generally.[5 6] A focus of future research should be to evaluate the psychometric properties of the tool with specific disease groups and disease-specific items.

There is evidence to suggest that the values of Australian First Nations people are not being adequately represented in available HR-QoL measures.[3] We have developed a culturally specific HR-QoL measure which has been conceptualised using Australian First Nations values of HR-QoL, which is acceptable for use and relative to other HR-QoL measures. Future research should expand on the further evaluation of the novel measure with larger and disease-specific populations, as well as evaluate its sensitivity when used to evaluate treatment.

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