





BMJ Open Health-related quality of life measures used with Indigenous children/youth in the Pacific Rim: a scoping review

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ABSTRACT

Objective To identify and describe (1) which health-related quality of life (HRQoL) measures have been used with Indigenous children/youth (aged 8–17 years) within the Pacific Rim; and (2) studies that refer to Indigenous health concepts in the use of child/youth HRQoL measures.

Design A scoping review.

Data sources Ovid (Medline), PubMed, Scopus, Web of Science and CINAHL were searched up until 25 June 2020.

Eligibility criteria Eligible papers were identified by two independent reviewers. Eligible papers were written in English, published between January 1990 and June 2020 and included an HRQoL measure used in research with Indigenous child/youth populations (aged between 8 and 17 years) in the Pacific Rim region.

Data extraction and synthesis Data extracted included study characteristics (year, country, Indigenous population, Indigenous sample size, age group), HRQoL measure characteristics (generic or condition-specific measure, child or adult measure, who completed the measure(s), dimensions, items and response scale of measure) and consideration of Indigenous concepts (created for Indigenous population, modified for Indigenous population, validated for Indigenous population, reliability in Indigenous populations, Indigenous involvement, reference to Indigenous theories/models/frameworks).

Results After removing duplicates, 1393 paper titles and abstracts were screened, and 543 had full-text review for eligibility. Of these, 40 full-text papers were eligible, reporting on 32 unique studies. Twenty-nine HRQoL measures were used across eight countries. Thirty-three papers did not acknowledge Indigenous concepts of health, and only two measures were specifically created for use with Indigenous populations.

Conclusions There is a paucity of research investigating HRQoL measures used with Indigenous children/youth and a lack of involvement of Indigenous peoples in the development and use of HRQoL measures. We strongly recommend explicit consideration of Indigenous concepts when developing, validating, assessing and using HRQoL measures with Indigenous populations.

INTRODUCTION

Internationally, Indigenous populations have models of health that include components that are not explicit in Western models. For example, Māori, the Indigenous population in

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Eligible papers were written in English, published between January 1990 and June 2020 and reported research including an Indigenous population from within a Pacific Rim country.
- ⇒ A limitation is that papers written in other languages published outside 1990–2020 or the Pacific Rim region will have been omitted.
- ⇒ The scoping review was limited to the current use of health-related quality of life measures (rather than a focus on the historical development of measures).
- ⇒ Strengths include searching across five large databases as advised by an experienced health sciences librarian, and dual independent screening for eligible papers (with differences reviewed by a third reviewer) as advised by scoping review methodologists.
- ⇒ Another strength of the scoping review is that it was led by a Māori PhD researcher (GM), supervised by two Māori academics (EW and SC), another Māori PhD researcher (VN) undertook the independent counter-reviewing and findings were discussed with members of a Māori Expert Advisory Group.

Aotearoa me Te Waipounamu (New Zealand; NZ), commonly conceptualise health using Māori health models such as Te Whare Tapa Whā,¹ Te Wheke² and the Meihana model.³ These health models reflect holistic views of health held by Māori, including concepts such as wairua (spiritual), whānau (family), taiao (environmental), identity and connection to Te Ao Māori (the Māori world). Further, health for Indigenous populations is often shaped by the effects of colonisation, marginalisation, migration and racism.^{4–8}

Article 24 of the United Nations Declaration on the Rights of Indigenous Peoples states that ‘Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health’⁹ (p 18). Historically, Indigenous population have been researched ‘on’ rather than ‘with’ or ‘for’.^{10–21} Despite the United Nations statement, Indigenous populations bear inequitable burdens of disease, disability



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and mortality compared with non-Indigenous populations.^{4 11 12 14 22–27} Additionally, Indigenous people experience poverty, inadequate healthcare, inadequate health promotion, poor disease prevention and inequities across almost all spheres of health compared with non-Indigenous people.²²

Health-related quality of life (HRQoL) measures are used to describe an individual's (or group's) HRQoL and to measure the impact of certain conditions on HRQoL, including changes resulting from treatment. They are also widely used by policy makers and funders to inform decision-making. HRQoL measures usually consider health across a number of dimensions compared with singular health outcome measures such as mortality rates, life expectancy or hospitalisation rates.^{28 29} HRQoL is typically described as a multifaceted concept incorporating factors such as physical, psychological and social health dimensions.³⁰ These factors align with WHO definition of health as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity'¹ (p 483). HRQoL measures can be generic, focusing on general HRQoL, or disease specific, focusing on particular health conditions (eg, oral health or diabetes).^{31 32} HRQoL measures have also been developed for use in child/youth populations.^{33–35}

Many adult HRQoL measures exist. However, HRQoL measures developed for adults may not be appropriate for children/youth. For instance, children/youth may have different views about health than adults, while younger children may have difficulty thinking about an abstract concept such as HRQoL or lack the vocabulary to fully describe their health.³⁶ Further, HRQoL measures for children/youth require a range of considerations including *what* aspects of HRQoL to measure, *who* should complete the measure (eg, children or parents/clinicians on their behalf), *how* to administer the measure (eg, paper, digital, interview) and, if required, how best to elicit preference weights (ie, to determine the relative importance of each HRQoL dimension).³⁷

Two recent comprehensive reviews describe the lack of appropriate HRQoL measures for Indigenous populations and the need to develop new measures specific for use with Indigenous populations.^{38 39} However, these reviews were undertaken with Indigenous adult populations; no such review appears to have been undertaken for child/youth HRQoL measures.

The identification of culturally relevant HRQoL measures for children/youth (should they exist) is vital to ensure that Indigenous children/youth HRQoL outcomes are appropriately assessed in research, clinical outcome and population health studies and surveys. This paper aims to: (1) identify and describe which HRQoL measures have been used with Indigenous children/youth (aged 8–17 years) within the Pacific Rim; and (2) identify and describe studies that refer to Indigenous health concepts in the use of child/youth HRQoL measures.

METHODS

The methods for this scoping review have been reported.⁴⁰ Briefly, papers eligible for the scoping review were written in English, published between January 1990 and June 2020, included an Indigenous population from within a Pacific Rim country and needed to:

...(1) refer to a HRQoL measurement/instrument/tool/questionnaire/scale/index/survey, (2) include a measure used in any child/youth population aged 8–17 years old and (3) include a measure used in any Indigenous population.⁴⁰ (p 5)

Papers were excluded if they:

1. Mentioned quality of life/disability-adjusted life year/quality-adjusted life year/global burden of disease but *did not* use a measure/instrument/tool/questionnaire/scale/index/survey.
2. Were not peer reviewed.
3. Were a review or protocol paper.
4. Did not use the full HRQoL measure/instrument/tool/questionnaire/scale/index/survey.
5. Included an Indigenous population not located in the Pacific Rim.
6. Included an Indigenous population but the findings for the Indigenous population were not able to be distinguished from those of non-Indigenous populations.

The search strategy was developed in Medline (Ovid) and adapted to five other databases including Ovid (Medline), PubMed, Scopus, Web of Science and CINAHL.⁴⁰

Ten abstracts were screened by GM and EW before proceeding to abstract reviews. Two reviewers (GM and VN) independently conducted abstract and then full-text reviews of identified papers, meeting at the beginning and end stages of the review process to discuss any challenges and uncertainties. A third independent reviewer (EW) then resolved any disputed decisions to reach a final consensus.

Data extracted from the papers included: year published, country, Indigenous population and country, Indigenous sample size, age of participants, HRQoL measure(s) used, who completed the measure(s) (eg, child/youth or a proxy completing on their behalf), dimensions included in the measure (ie, physical, mental, school), response scales (eg, 1=no problems, 5=a lot of problems) and authors' reports on if the HRQoL measure was created, modified, validated or found to be reliable for an Indigenous population. Papers were descriptively summarised as per the scoping review objectives and questions. The scoping review has not been registered.

Patient and public involvement

This scoping review is part of a larger PhD project led by a Māori researcher (GM) and supervised by two very experienced Māori researchers (EW and SC), and two non-Māori researchers (TS and SD) who all have vast kaupapa Māori, Māori health, rangatahi health and health research expertise. Indigenous research often includes

Indigenous community involvement in the research process, and in this instance included a Māori Expert Advisory Rōpū (group) established to provide guidance, support and ensure culturally safe and meaningful research for the overall research project. Specifically for this paper, another Māori PhD researcher (VN) counter-reviewed abstracts and full texts. The Māori Expert Advisory Rōpū provided guidance on the interpretation of the scoping review results, as per step 6 of the scoping review method.^{41 42}

RESULTS

The search yielded 2207 papers (figure 1). Once duplicates were removed, 1393 unique abstracts were reviewed. Of these, 543 were eligible for full-text review. A reference list search of the eligible 543 papers led to a further 12 papers being examined for inclusion. After full-text review, a total of 40 papers were retained, reporting findings from 32 distinct studies.^{43–84}

Study settings and cohorts

The scoping review included 40 eligible papers (table 1). Thirteen papers reported research from Australia,^{46 49 50 52 53 57 60 63 65 71 72 78 79} seven from Canada,^{43 62 66 81–84} six from NZ^{44 45 48 56 76 85} and Fiji,^{54 59 68 69 73 75} three from the USA,^{51 67 74} one from Taiwan,⁸⁰ one from Malaysia⁴⁷ and one from Tonga.⁵⁵ Two papers focused on Indigenous populations from two countries: NZ and Australia⁶⁴ and Tonga and NZ.⁷⁰ A range of Indigenous populations were included within these eight countries. Twelve papers had 100% Indigenous participants, ranging from 15 to 1396 people.^{46–48 50 53 55 80–84}

Ages of participants ranged from <1 (infants) to 77 years. Thirty-three papers were specific to child/youth populations,^{43–45 47–49 52 54–57 59 60 62–65 67–73 76–84} while six focused on all ages (including child/youth).^{46 50 51 53 74 75} One paper focused on boys only,⁵⁰ 39 papers on girls and boys; no papers reported on gender diverse populations.

Six papers drew on one large Pacific Obesity Prevention in Communities (OPIC) study.^{55 59 68–70 73} Four papers reported on the reliability, validity and relevance of one Indigenous measure (Aboriginal Children's Health and Well-being Measure; ACHWM).^{81–84} The remaining 30 papers reported unique studies.

HRQoL measures

In total, 29 different HRQoL measures (or variations of measures) were used (tables 2 and 3). The Paediatric Quality of Life Inventory (PedsQL) (including the PedsQL 3.0 Diabetes Module, a variation of the PedsQL) was reported in 16 papers,^{43 45 49 52 55 57 59 63 65 68–71 73 82 84} and the Oral Health Impact Profile (OHIP-14) in three papers.^{47 48 60} Ten papers used two or more HRQoL measures.^{43 49 55 59 60 64 66 74 82 84}

Of the 40 papers, 23 used HRQoL measures developed specifically for use among child/youth populations,^{43 45 49 52 54 56 57 60 62–66 71 72 74 76–79 81–84} while 10 papers

used adult HRQoL measures where HRQoL was self-reported by child/youth populations.^{44 46–48 50 51 53 67 75 80} Both a child/youth HRQoL measure *and* an adult HRQoL measure were reported in two of the six papers produced from the OPIC study.^{55 59}

Twenty-five papers used generic HRQoL measures only.^{44–46 50 52 55 57 59 62 63 65 67–73 75 79–84} Eleven papers used disease-specific HRQoL measures only,^{47 48 51 53 54 56 64 74 76–78} the most common being oral HRQoL measures^{47 48 56 76 85}—the OHIP-14,^{47 48} the Child Perceptions Questionnaire for children aged 11–14 years^{76 85} and the Child Oral Health Quality of Life Questionnaire.⁵⁶ Four papers used both disease-specific and generic HRQoL measures.^{43 49 60 66}

Measure characteristics

Just over half of the papers (n=23) comprised self-reported HRQoL data (ie, children/youth rated their own health),^{44 46–48 50 51 53 54 59 67–71 73 75 76 80–85} eight papers were parent proxy reported,^{49 52 56 57 62 65 72 79} six papers collected both parent proxy and self-reported data^{43 45 63 64 66 74} and two papers did not state who completed the HRQoL measure.^{55 60}

Five preference-based HRQoL measures were identified, all of which were generic. Two were child/youth-specific measures (Child Health Utility-9 Dimensions⁶⁰ and Quality of My Life Questionnaire⁶⁶); the remaining were adult measures used with children/youth (the Assessment of Quality of Life-6 Dimensions (two papers)^{55 59} and the Short Form-6 Dimensions).⁴⁶ Self-report by children/youth was used in two of these adult measures,^{46 59} and the remaining paper did not state who completed the measure.⁵⁵

Consideration of Indigenous concepts/theories/frameworks

Among the included papers, 33 did not acknowledge Indigenous concepts of health (table 4). Two Indigenous-specific measures were identified; the Wicozani Instrument⁶⁷ and the ACHWM.^{81–84} Two other papers referred to Indigenous theories, models or frameworks to varying degrees.^{53 76}

In Eley's study,⁵³ an intervention based on traditional Aboriginal practices for improved health and cultural benefits was trialled. Specifically, traditional music medicine interventions, including use of the didgeridoo, were investigated, with the aim of improving management of chronic asthma in various Aboriginal and Torres Strait Islander age groups. The Asthma Quality of Life Questionnaire (Juniper's version) was used in two out of the seven intervention groups. However, the authors noted that this measure did not provide interpretable results primarily due to a lack of completion by the participants, and suggested that the measure was not culturally suitable; however, no further insights were provided.

One further study acknowledged some Indigenous concepts.⁷⁶ Traebert *et al's*⁷⁶ study, which involved Māori participants, commented that HRQoL is linked to aspects of Māori views of well-being such as wairua and whānau, and that these components are equally important to

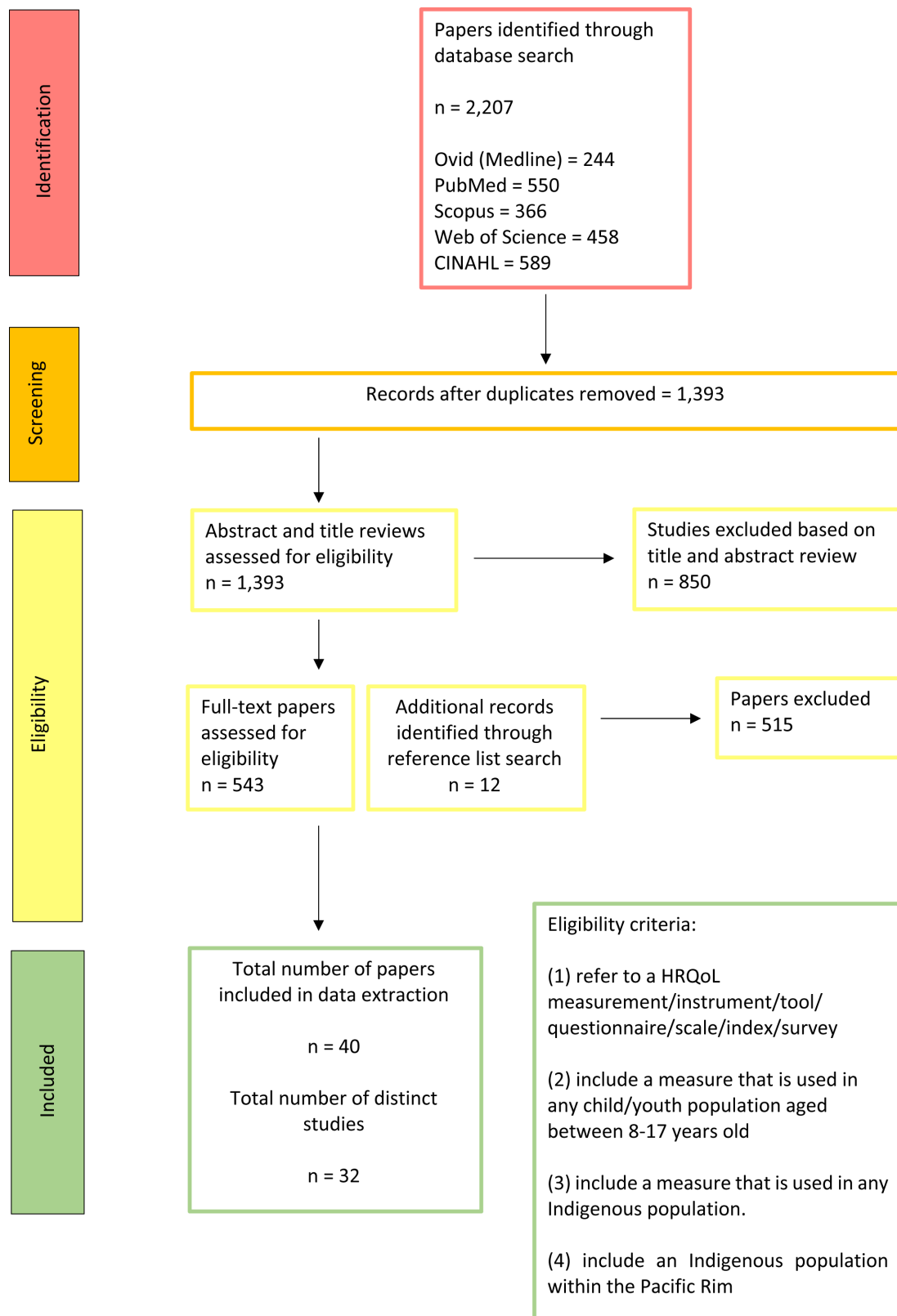


Figure 1 Scoping review literature search flow diagram. HRQoL, health-related quality of life.

physical and mental domains. However, apart from raising these issues, this study did not address these concepts further.

Chenhall *et al*⁵⁰ did not explicitly refer to Indigenous theories when describing their study that included the

Schedule for the Evaluation of Individual Quality of Life-Direct Weighting for Australian Indigenous male youth.⁵⁰ However, the open-ended questioning allowed the youth participants to determine the most important aspect of health for themselves⁵⁰ which provided an opportunity

Table 1 Summary of study settings and cohorts identified in scoping review

Reference	Year	Country as reported in the paper	Indigenous population as reported in the paper	Indigenous sample size (%)	Age (years)
Kularatna <i>et al</i> ⁶⁰	2020	Australia (Far North Queensland)	Aboriginal and Torres Strait Islander	n=unreported/408 (>95%)	5–16
Banham <i>et al</i> ⁴⁶	2019	(South) Australia	Aboriginal	n=399 (100%)	15+ 15–24 n=30.4%
Del Pozo-Cruz <i>et al</i> ⁵²	2019	Australia	Indigenous	0–5 years old n=unreported/4164 (2.61%) 4–9 years old n=85 unreported/3974 (2.13%)	0–9
Lord <i>et al</i> ⁶³	2019	Australia	Aboriginal and Torres Strait Islander	n=52/1020 (5.1%)	<5–18
Lovie-Toon <i>et al</i> ⁶⁴	2019	Australia and New Zealand	Indigenous Australian/New Zealand	34/85 Indigenous Australian/Māori (40%)	5.4–11.3
Chang <i>et al</i> ⁴⁹	2013	Australia	Indigenous Australians	n=15/238 (11.7%)	1–8
Eley ⁵³	2013	Australia	Aboriginal and Torres Strait Islander	n=75 (100%) Study group where QoL measure was used n=15	5–77 Study group QoL measure used in 13–18 (n=15)
Jansen <i>et al</i> ⁵⁷	2013	Australia	Indigenous	n=unreported/3898 (3.5%)	4–11 (longitudinal study, 4–5 then followed up 10–11)
Mensah <i>et al</i> ⁶⁵	2013	Australia	Aboriginal and Torres Strait Islander	n=unreported/3491 (3%)	4–5 with follow-ups at ages 6–7, 8–9 and 10–11
Wark <i>et al</i> ⁷⁹	2013	Australia	Aboriginal and Torres Strait Islander	n=62/68 (91%)	9–11
Sawyer <i>et al</i> ⁷²	2011	Australia	Aboriginal and Torres Strait Islander	n=unreported/3363 (2%) 7% lost to follow-up	4–5 with follow-up at 8–9
Chenhall <i>et al</i> ⁵⁰	2010	Australia	Indigenous youths	n=15 (100%) (male)	14–19
Sawyer <i>et al</i> ⁷¹	2010	Australia	Indigenous Australians	Remand group n=unreported/159 (35.8%) Australian National Survey n=unreported/1283 (3.5%)	13–17
Valery <i>et al</i> ⁷⁸	2010	Australia	Aboriginal and Torres Strait Islander	n=does not state/88 (98%)	1–17
Oen <i>et al</i> ⁶⁶	2018	Canada	‘Aboriginal’	n=105/1249 (8.8%)	Does not state
Levy <i>et al</i> ⁶²	2014	Canada	‘Aboriginal’	n=8/196 (4%)	5–18
Allan <i>et al</i> ⁴³	2008	Canada	First Nations (Oji-Cree)	n=26/28 50:50 parent:youth Youth population with Indigenous ancestry (89.3%)	7–18
Anderson <i>et al</i> ⁴⁵	2017	New Zealand	Māori	n=unreported/233 (45%)	4.8–16.8

Continued

Table 1 Continued

Reference	Year	Country as reported in the paper	Indigenous population as reported in the paper	Indigenous sample size (%)	Age (years)
Aminzadeh <i>et al</i> ⁴⁴	2013	New Zealand	Māori and Pacific Island peoples	Māori n=1044/5508 (19%) Pacific n=578/5508 (10.5%)	13–17
Ukra <i>et al</i> ⁷⁷	2013	New Zealand	Māori	n=113/783 (14.4%)	12–13
Broughton <i>et al</i> ⁴⁸	2012	New Zealand	Māori	n=238 (100%)	16–18
Gaynor and Thomson ⁵⁶	2012	New Zealand	Māori and Pacific Island peoples	Māori n=32/157 (20.4%) Pacific Islander n=58/157 (36.9%)	0–9
Traebert <i>et al</i> ⁷⁶	2010	New Zealand	Māori	n=88/430 (20.5%)	12–13
Fang <i>et al</i> ⁵⁴	2016	Fiji	Fijian and Rotuman	Fijian n=196/467 (unreported %) Rotuman n=17/467 (unreported %)	0–18
Thomson Mangnall <i>et al</i> ⁷⁵	2014	Fiji	Indigenous Fijian	n=79/128 (62%)	12–55
Peters <i>et al</i> ⁶⁷	2019	USA (Dakota)	'native'	n=50/138	Mean age 6th graders=11.17 Mean age 10th graders=15.21
Daubs <i>et al</i> ⁵¹	2014	USA	Native American Indian, Alaska Native and Pacific Island peoples	Native American Indian/Alaska Native n=140/3052 (4.9%) Pacific Islander n=105/3052 (3.7%)	10–19
Skirko <i>et al</i> ⁷⁴	2013	America	American Indian	n=3/84 (4%)	3–22
Berhan Nordin <i>et al</i> ⁴⁷	2019	Malaysia	Orang Asli (OA)	n=227 (100%)	11–12
Wu ⁸⁰	2014	Taiwan	Indigenous Taiwanese	n=152 (100%)	11–15
Young <i>et al</i>⁸¹	2017	Canada	First Nations and Inuit	n=44 (23 children, 21 caregivers) (100%)	8–18
Young <i>et al</i>⁸³	2015	Canada	First Nations	n=48 (100%)	7–19
Young <i>et al</i>⁸⁴	2015	Canada	First Nations	n=18 (9 children, 9 caregivers) (100%)	8–18
Young <i>et al</i>⁸²	2016	Canada	First Nations	n=256 (100%)	8–18
<i>Sinclair <i>et al</i>⁷³</i>	2016	<i>Fiji</i>	<i>Indigenous Fijian</i>	<i>n=3077/7237 (42.5%)</i>	<i>13–18</i>
<i>Petersen <i>et al</i>⁶⁹</i>	2014	<i>Fiji</i>	<i>Indigenous Fijian</i>	<i>n=3725/8947 (41.6%)</i>	<i>12–18</i>
<i>Petersen <i>et al</i>⁶⁸</i>	2012	<i>Fiji</i>	<i>Indigenous Fijian</i>	<i>n=3725/8947 (41.6%)</i>	<i>12–18</i>
<i>Kremer <i>et al</i>⁵⁹</i>	2011	<i>Fiji</i>	<i>Indigenous Fijian</i>	<i>n=956/2948 (32.4%)</i>	<i>13–18</i>
<i>Petersen <i>et al</i>⁷⁰</i>	2014	<i>Tonga and New Zealand</i>	<i>Indigenous</i>	<i>n=2123/2164 (98.1%)</i>	<i>11–18</i>
<i>Fotu <i>et al</i>⁵⁵</i>	2011	<i>Tonga</i>	<i>Tongan</i>	<i>100% Tongan Intervention n=1083 (follow-up n=815) Comparison n=1396 (follow-up n=897)</i>	<i>11–19</i>

Bold denotes part of a larger study on developing the Aboriginal Children's Health and Well-being Measure (ACHWM). Italic denotes part of a larger study: OPIC.

OPIC, Obesity Prevention in Communities; QoL, quality of life.

Table 2 Characteristics of generic HRQoL measures

Reference	Measure	Child/Adult	Age (years)	Who completed	Dimensions (items) as reported in the paper	Response scale as reported in the paper
Generic measures						
Anderson <i>et al</i> ⁶⁵	PedsQL 4.0	Child	4.8–16.8	Both child self-rated and parent proxy report	4 dimensions: physical, emotional, social and school functioning (total=23)	–
Del Pozo-Cruz <i>et al</i> ⁶²	PedsQL	Child	0–9	Parent proxy	23 items	–
Jansen <i>et al</i> ⁶⁷	PedsQL	Child	4–11	Parent/caregiver proxy	4 dimensions: physical health (8 items), emotional function (5 items), social functioning (5 items), school functioning (5 items). In the preschooler wave this consisted of only 3 items in each.	5-point scale, ranging from 0=‘never a problem’ to 4=‘almost always a problem’
Lord <i>et al</i> ⁶³	PedsQL	Child	14–49	Parent proxy and child self-complete (age appropriate) (5–7 years assisted by a clinician or parent)	4 dimensions: physical, emotional, social and school functioning (23 items total)	5-point scale where 0=Never (a problem), 1=Almost never, 2=Sometimes, 3=Often and 4=Almost always. For children aged 5–7 years, the scale is clinician administered and rated on a 3-point scale.
Mensah <i>et al</i> ⁶⁵	PedsQL	Child	5.4–11.3	Parent proxy	–	–
Sawyer <i>et al</i> ⁷²	PedsQL 4.0	Child	12–18	Parent/caregiver proxy	4 dimensions: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items) and school functioning (5 items)	Respondents answered each item using a 5-point scale with endpoints labelled ‘never’ and ‘almost always’.
Petersen <i>et al</i> ⁶⁸	PedsQL 4.0	Child	12–55	Self-report	4 dimensions: physical, emotional, social, and school functioning and well-being (23 items total)	Five response choices on an ordinal scale ranging from ‘never’ (0) to ‘almost always’ (5)
Petersen <i>et al</i> ⁶⁹	PedsQL 4.0	Child	12–13	Self-report	4 dimensions: physical (8 items), emotional (5 items), social (5 items) and school functioning (5 items)	Response alternatives were given on a 5-point scale (never, almost never, sometimes, often and almost always a problem) with a recall time of 1 month.
Petersen <i>et al</i> ⁷⁰	PedsQL 4.0 (Tongan language)	Child	12–13	Self-report	4 dimensions: physical (8 items), emotional (5 items), social (5 items) and school functioning (5 items)	Items have five response alternatives ranging from (0) ‘never’ to (4) ‘almost always a problem’.
Sinclair <i>et al</i> ⁷³	PedsQL 4.0	Child	9–11	Self-report	4 dimensions: physical (8 items), emotional (5 items), social functioning (5 items) and school functioning (5 items)	–
Fotu <i>et al</i> ⁶⁵	AQoL-6D PedsQL 4.0	Adult Child	11–19	Does not state	–	–
Kremer <i>et al</i> ⁵⁹	AQoL-6D PedsQL 4.0	Adult Child	13–18	Self-report	–	–
Young <i>et al</i> ⁸³	ACHWM PedsQL	Child Child	7–19	Self-report	4 dimensions: spiritual, emotional, physical and mental health	–
Young <i>et al</i> ⁸⁴	ACHWM PedsQL	Child Child	8–18	Self-report	4 dimensions: spiritual (15 items), emotional (22 items), physical (12 items) and mental (9 items)	–
Young <i>et al</i> ⁸²	ACHWM	Child	8–18	Self-report	4 dimensions: spiritual, emotional, physical and mental (62 items total)	–

Continued

Table 2 Continued

Reference	Measure	Child/Adult	Age (years)	Who completed	Dimensions (items) as reported in the paper	Response scale as reported in the paper
Young <i>et al</i> ⁶¹	ACHWM	Child	8–18	Self-report	4 dimensions: spiritual, emotional, physical and mental (62 items total)	–
Wu ⁸⁰	WHOQOL-BREF	Adult	11–15	Self-report	4 dimensions: physical health, psychological health, social relationships, environment	–
Levy <i>et al</i> ⁶²	CHQ parent report	Child	5–18	Parent/caregiver	10 mental and physical dimensions: physical functioning; bodily pain; general health perceptions; role/social limitations—physical; role/social limitations—emotional/behavioural; parent impact—time; parent impact—emotional; self-esteem; mental health; general behaviour	–
Sawyer <i>et al</i> ⁷¹	CHQ	Child	μ 6th graders=11.17 μ 10th graders=15.21	Self-report	3 dimensions: physical activities (physical functioning), pain and discomfort (bodily pain) and perceived interference with school and peer activities (role/ social)	–
Wark <i>et al</i> ⁷⁹	CHQ-PF28	Child	4–9	Parent proxy	2 dimensions: physical and psychosocial concepts (14 items total)	Each domain is scored from 0 to 100, with 0 indicating poor and 100 excellent health and functioning.
Banham <i>et al</i> ⁶⁶	SF-6D	Adult	15+	Self-report	6 dimensions: physical function, role limitation, social function, bodily pain, mental health and vitality	–
Thomson Mangnall <i>et al</i> ⁷⁵	SF-36v2	Adult	12–18	Self-report	8 dimensions: physical function; role limitations due to physical health (role-physical); bodily pain; general health; energy/fatigue (vitality); social function; role limitations due to emotional problems (role-emotional) and mental health (36 items total)	–
Aminzadeh <i>et al</i> ⁴⁴	WHO-5	Adult	<13–17+	Self-report	5 dimensions (1 item each): 'I have felt cheerful and in good spirits'; 'I have felt calm and relaxed'; 'I have felt active and vigorous'; 'I woke up feeling fresh and rested'; 'my daily life has been filled with things that interest me'	The response alternatives were 'all of the time', 'most of the time', 'more than half of the time', 'less than half of the time', 'some of the time' or 'at no time'.
Chenhall <i>et al</i> ⁵⁰	SEIQoL-DW	Adult	14–19	Self-report	Open-ended question measure; asks the respondent to nominate the five most important areas of their own life.	Rate on a 10-point scale their level of functioning in each life domain. Then to determine the relative importance of each life area.
Daubs <i>et al</i> ⁵¹	SRS-22	Adult	10–19	Self-report	4 dimensions: function, pain, image and mental	–
Peters <i>et al</i> ⁶⁷	Wicozani Instrument	Adult	4–11	Self-report	3 dimensions: mental, physical and spiritual health (9 items total)	Two 5-point scales: (a) ranging from extremely poor (1) to excellent (5); and (b) ranging from very unimportant (1) to very important (5)
ACHWM, Aboriginal Children's Health and Well-being Measure; AQoL-6D, Assessment of Quality of Life-6 Dimensions; CHQ, Child Health Questionnaire; CHQ-PF28, Child Health Questionnaire Parent-reported Form 28 items; HRQoL, health-related quality of life; PedsQL, Paediatric Quality of Life Inventory; SEIQoL-DW, Schedule for the Evaluation of Individual Quality of Life-Direct Weighting; SF-6D, Short Form-6 Dimensions; SF-36v2, Short Form-36 Health Survey Questionnaire version 2; SRS-22, Scoliosis Research Society Outcomes Questionnaire-22; WHO-5, WHO-Five Well-being Index; WHOQOL-BREF, WHO Quality of Life-BREF.						

Table 3 Characteristics of papers using both ‘disease and generic’ and disease only HRQoL measures

Reference	Measure	Child/ Adult	Age (years)	Who completed	Dimensions (items) as reported in the paper	Response scale as reported in the paper
Disease and generic measures						
Allan <i>et al</i> ⁴³	PedsQL 3.0 (Diabetes Module) PedsQL 4.0	Child Child	7–18	Both child self-report and parent proxy report	PedsQL 3.0 (Diabetes Module)—five dimensions: diabetes symptoms (11 items), diabetes treatment (4 items), diabetes treatment II (7 items), diabetes worry (3 items), communication (3 items) PedsQL 4.0—four dimensions: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), school functioning (5 items)	5-point Likert scale from 0 to 4 (0=Never, 1=Almost never a
Chang <i>et al</i> ⁴⁹	PC-QoL PedsQL	Child Child	1–8	Parent proxy	–	–
Kularatna <i>et al</i> ⁶⁰	OHIP-14 CHU9D	Child	13–18	Does not state	–	–
Oen <i>et al</i> ⁵⁶	JAQQ CoML	Child Child	Does not state	>9 self-complete <9 parent proxy	JAQQ—four dimensions: gross motor, fine motor, psychosocial and systemic symptoms CoML—does not state	JAQQ—seven responses (1—no difficulty with a given activity to 7—difficulty 100% of the time) CoML—does not state
Disease-specific measures						
Bergman-Nordén <i>et al</i> ⁴⁷	OHIP-14	Adult	14–42	Self-report	8 dimensions: eating, speaking, clearing teeth, relaxing, smiling, maintaining emotional stability, studying and socialising	8-point rating scale, ‘more than 3 times a day’, ‘2–3 times a day’, ‘once a day’, ‘2–3 times a week’, ‘once a week’, ‘once a month’, ‘once in 2–12 months’ and ‘never’
Broughton <i>et al</i> ⁴⁸	OHIP-14	Adult	16–18	Self-report 7 dimensions: functional limitation (2 items), physical pain (2 items), psychological discomfort (2 items), physical disability (2 items), psychological disability (2 items), social disability (2 items), handicap (2 items)	Responses were coded as ‘Very often’ (scoring 4), ‘Fairly often’ (scoring 3), ‘Occasionally’ (scoring 2), ‘Hardly ever’ (scoring 1) or ‘Never’ (scoring 0).	Traebert <i>et al</i> ⁷⁶
CPQ 11–14	Child	11–18	–	4 dimensions: oral symptoms (6 items), functional limitations (9 items), emotional well-being (9 items) and social well-being (13 items)	The response options were: never (0), once / twice (1), sometimes (2), often (3) and every day/almost every day (4).	Ukra <i>et al</i> ⁷⁷
CPQ 11–14	Child	13–17	Self-report	4 dimensions: oral symptoms (4 items), functional limitations (4 items), emotional well-being (4 items) and social well-being (4 items)	Response options and scores were: ‘Never’ (0); ‘once or twice’ (1); ‘Sometimes’ (2); ‘Often’ (3); and ‘Every day or almost every day’ (4).	Gaynor and Thomson ⁵⁶

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Table 3 Continued

Reference	Measure	Child/Adult	Age (years)	Who completed	Dimensions (items) as reported in the paper	Response scale as reported in the paper
COHQoL (P-COQ and FIS)	Child	0–9	Parent proxy	P-COQ—four dimensions: oral symptom (6 items), functional limitation (5 items), emotional well-being (9 items) and social well-being (10 items) FIS—three dimensions: parental/family activity (5 items), parental emotions (4 items) and family conflict (4 items)	3-point Likert-type responses: 0, 'never'; 1, 'often'; 2, 'sometimes'; 3, 'often'; 4, 'every day or almost every day'. A 'don't know' response was also offered and scored as 0.	Skirko et al ⁷⁴
VELO Parent, VELO Youth, PVOS, PVRQOL	Child	3–22	VELO Parent—parent proxy VELO Youth—self-complete PVOS and PVRQOL—self-complete	–	VELO (Parent) and VELO (Youth)—5-point Likert scale ranging from never (0) to almost always (4) PVOS and PVRQOL—does not state	Eley ⁵³
AGQ (Juniper's)	Adult	5–77	Self-report	–	7-point scale where 1 indicates maximum impairment and 7 indicates no impairment	Valery et al ⁷⁸
PAC-QoL	Child	1–17	Self-complete and parent proxy	–	–	Tran et al ⁶⁴
PC-QoL, CC-QoL	Child	<5–18	Parent/carer proxy (PC-QoL) and/or child reported (>7 years; CC-QoL)	–	–	Fang et al ⁵⁴
OM-6	Child	0–18	Self-report	6 dimensions: physical suffering, hearing loss, speech impairment, emotional distress, activity limitation, caregiver concerns	1 (none), 2 (hardly), 3 (somewhat), 4 (moderate), 5 (quite a bit), 6 (very much), 7 (extreme)	AQLQ (Juniper's), Asthma Quality of Life

for cultural, social and political factors influencing health to be included in responses.

Nine papers explicitly mentioned the inclusion of an Indigenous researcher or that research was carried out under the guidance of an Indigenous Elder.^{43 48 50 53 67 81–84} Seven papers included ethical approval from an Indigenous committee,^{43 46 71 78 82–84} and one paper was undertaken with the formal approval of Elders.⁶⁰

Development of Indigenous-specific measures

Only two of the 29 measures identified in the scoping review were created specifically for use with Indigenous populations: one was a child/youth-specific measure (ACHWM^{81–84}), and the other an adult measure (the Wicozani Instrument⁶⁷).

The ACHWM^{81–84} was developed specifically for use with First Nations children within the Wikwemikong Unceded Indian Reserve, Canada, who collectively identify as Anishinabek. This measure, developed in 2013, is intended to be independently completed via tablet by children/youth aged 8–18 years. Further, the measure is grounded in Indigenous epistemology, and focuses on feelings and perceptions of health rather than health behaviours.⁸³

The ACHWM^{81–84} contains four dimensions: spiritual (15 items), emotional (22 items), physical (12 items) and mental (9 items), adding to 60 multiple-choice questions. The questions were generated through the inclusion of items from the PedsQL, Strong Souls (an Indigenous social and emotional well-being measure),⁸⁶ advisory

committee meetings, community consultation sessions and photovoice data.⁸⁷

The ACHWM^{81–84} has since been validated,^{83 84} assessed for children's (and caregivers') interpretation,⁸⁴ tested for reliability⁸² and more recently extended for use with other Indigenous populations, specifically for other First Nations, Inuit and Métis children/youth.⁸⁷ Part of the validation included Pearson's correlation between the total ACHWM score and total PedsQL aggregate score (ACHWM mean=71.4; PedsQL mean=71.1; $r=0.52$, $p=0.0001$),⁸³ providing a moderate positive correlation.⁸⁸

There are a number of possible limitations with the ACHWM^{81–84} instrument. First, the cluster of studies related to the ACHWM is limited to small groups of children/youth, and is focused primarily on one community. Second, although there were separate studies, there may have been overlap of participants due to the study area being the same Wikwemikong Unceded Indian Reserve. Finally, the measure contains 60 questions, which is lengthy for children/youth to answer and consequently a potential barrier for use.

A strength of this research using the ACHWM^{81–84} was the diversity of participants in terms of ages (8–18 years), genders and diverse community involvement (including areas of Odawa, Ojibway and Pottawatomi as part of the Anishinabek people).^{81–84 87} Additionally, this research was conducted in a culturally appropriate way, coled by a First Nation health director and an academic researcher who worked in collaboration with other Aboriginal

Table 4 Consideration of Indigenous concepts (as reported in the paper)

Reference	HRQoL measure	Created for Indigenous population	Modified for Indigenous population	Validated for Indigenous population	Reliability in Indigenous population	Indigenous involvement	Refer to Indigenous theories/models/frameworks
Allan <i>et al</i> ⁴³	PedsQL 3.0 (Diabetes Module) PedsQL 4.0	No	No	No	No	A First Nation research assistant conducted all aspects of the study in the clinic and approved by the Manitoba First Nations Diabetes Committee.	No
Aminzadeh <i>et al</i> ⁴⁴	WHO-5	No	No	No	No	None stated	No
Anderson <i>et al</i> ⁴⁵	PedsQL 4.0	No	No	No	No	None stated	No
Banham <i>et al</i> ⁴⁶	SF-6D	No	No	No	No	Study approved by the Aboriginal Health Council of South Australia.	No
Berhan Nordin <i>et al</i> ⁴⁷	OHIP-14	No	No	Tested for face validity on 20, 11–12 year-olds. No changes were made to any of the items.	None declared	None stated.	No
Broughton <i>et al</i> ⁴⁸	OHIP-14	No	No	States that 'it appears that the measure has validity for such use' in rangatahi Māori.	None declared	Study led by an Indigenous academic, conducted in collaboration with Raukura Hauora O Tainui and the survey was conducted by two specifically trained Māori health research assistants.	No
Chang <i>et al</i> ⁴⁹	PC-QoL PedsQL	No	No	No	No	None stated	No
Chenhall <i>et al</i> ⁵⁰	SEIQoL-DW	No	No, however chose this specific QoL measure for the Indigenous population in the study due to its questioning nature.	No	No	Camps (that the study population were derived from) were run by an Indigenous organisation. The SEIQoL-DW was administered by the Indigenous staff.	No
Daubs <i>et al</i> ⁵¹	SRS-22	No	No	No	No	None stated	No
Del Pozo-Cruz <i>et al</i> ⁵²	PedsQL	No	No	No	No	None stated	No
Eley ⁵³	AQLQ (Juniper's)	No	No	No	No	5/6 teachers who were employed identified as being an Aboriginal Australian. Each school had an Indigenous person in the position of Indigenous liaison officer, and they facilitated the advertising and parental consent process.	Not relating directly to the HRQoL measure; however, the intervention (music medicine intervention with specific use of the didgeridoo) was based around traditional Aboriginal practices for improved health and cultural benefits.
Fang <i>et al</i> ⁵⁴	OM-6	No	No	No	No	None stated	No
Fotu <i>et al</i> ⁵⁵	AQoL-6D PedsQL 4.0	No	AQoL-6D version that was specifically calibrated for the Tongan adolescent population.	No	No	Ethical approval from the Tonga National Health Ethics Research Committee.	No
Gaynor and Thomson ⁵⁶	Based on the COHQoL (made up of P-CPQ and the FIS)	No	No	Suggests that the 'concept of OHRQoL transcends cultural differences'.	No	None stated	No
Jansen <i>et al</i> ⁵⁷	PedsQL	No	No	No	No	None stated	No

Continued

Table 4 Continued

Reference	HRQoL measure	Created for Indigenous population	Modified for Indigenous population	Validated for Indigenous population	Reliability in Indigenous population	Indigenous involvement	Refer to Indigenous theories/models/frameworks
Kremer <i>et al</i> ⁶⁹	AQoL-6D PedsQL 4.0	No	No; however, the survey items were piloted in Fiji to ensure clarity and cultural and general relevance. No modifications were made.	No	No	None stated (although there was an author from Fiji National University and another from the National Food and Nutrition Centre (Suva)).	No
Kularatna <i>et al</i> ⁶⁰	OHIP-14 CHU-9D	No	No	No	No	The study was undertaken with the formal permission of the Elders.	No
Levy <i>et al</i> ⁶²	CHQ parent report	No	No	No	No	No	No
Lord <i>et al</i> ⁶³	PedsQL	No	No	No	No	None stated	No
Lovie-Toon <i>et al</i> ⁶⁴	PC-QoL Children >7 years; CC-QoL	No	No	No	No	None stated	No
Mensah <i>et al</i> ⁶⁵	PedsQL	No	No	No	No	None stated	No
Oen <i>et al</i> ⁶⁶	JAQQ and GoML	No	No	No	No	No	No
Petersen <i>et al</i> ⁶⁸	PedsQL 4.0	No	No; however, the survey items were piloted in Fiji to ensure clarity and cultural and general relevance. No modifications were made.	No	No	None stated (one author affiliated to health organisations in Fiji).	No
Petersen <i>et al</i> ⁶⁹	PedsQL 4.0	No	No	No	No	None stated (one author is affiliated to the University of Fiji).	No
Petersen <i>et al</i> ⁷⁰	PedsQL 4.0	No	Translated into Tongan.	No	No	None stated (one author is affiliated to the University of Fiji).	No
Peters <i>et al</i> ⁶⁷	Wicozani Instrument	Yes	N/A—created for Indigenous population.	States: evidence of validity and reliability of the Wicozani Instrument.	Grounded in Indigenous paradigms such as the Dakota concept of wicozani, overall health and well-being, including mental, physical and spiritual health.	Dakota Wicohan research partners included several staff, elder advisors and board members, all from the Dakota community. The research team member and three research assistants were Indigenous.	No
Sawyer <i>et al</i> ⁷¹	CHQ	No	No	No	No	None mentioned; however, the study was approved by the Aboriginal Health and Research Ethics Committee in South Australia.	No
Sawyer <i>et al</i> ⁷²	PedsQL 4.0	No	No	No	No	None stated	No
Sinclair <i>et al</i> ⁷³	PedsQL 4.0	No	No	No	No	None stated (one author is affiliated to the University of Fiji).	No
Skirko <i>et al</i> ⁷⁴	VELO Parent VELO Youth PVOS PVRQOL	No	No	No	No	No	No
Thomson Mangnall <i>et al</i> ⁷⁵	SF-36v2	No	Modification of examples provided in the questions.	No	No	None stated	No

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Table 4 Continued

Reference	HRQoL measure	Created for Indigenous population	Modified for Indigenous population	Validated for Indigenous population	Reliability in Indigenous population	Indigenous involvement	Refer to Indigenous theories/models/frameworks
Traibert <i>et al</i> ⁷⁶	CPQ 11–14	No	No	No	No	None stated	Acknowledges Māori health includes wairua, whānau, physical and mental dimensions. However, did not report measuring constructs that reflect their values and beliefs so cannot expand on these in this group.
Ukra <i>et al</i> ⁷⁷	CPQ 11–14	No	No	No	No	None stated	No
Valery <i>et al</i> ⁷⁸	PAQLQ	No	No	No	No	Conducted by Australian Indigenous healthcare workers. Ethical approval by the Torres Strait Regional Health Council and the Torres Strait and Northern Peninsula Area Health Service District.	No
Wark <i>et al</i> ⁷⁹	CHQ-PF28	No	No	No	No	None stated	No
Wu ⁸⁰	WHQoL–BREF	No	WHQoL–BREF—translated into Mandarin Chinese.	No	No	No	No
Young <i>et al</i> ⁸³	ACHWM PedsQL	Yes	N/A—created for Indigenous population.	Yes: the validity of the ACHWM was assessed in comparison to the PedsQL (ACHWM mean=71.4; PedsQL mean=71.1; $r=0.52$; $p=0.0001$).	No	Coled by a First Nation health director, and also worked in collaboration with other Aboriginal health leaders and Elders (one of whom is an author on the paper). Approved by the First Nation's chief and council and the Manitoulin Anishinaabek Research Review Committee.	Based on the Medicine Wheel Framework, which includes questions to assess each of the 4 quadrants (or domains) of health: spiritual, emotional, physical and mental. ACHWM is unique in including a series of questions reflecting spirituality, which is a critically important domain in Aboriginal health frameworks.
Young <i>et al</i> ⁸⁴	ACHWM PedsQL	Yes	N/A—created for Indigenous population.	Yes	Yes	Coled by a First Nation health director (MJW), and also worked in collaboration with other Aboriginal health leaders and Elders. Study was also approved by the Manitoulin Anishinaabek Research Review Committee.	Based on the Medicine Wheel Framework, which includes questions to assess each of the 4 quadrants (or domains) of health: spiritual, emotional, physical and mental.

Continued

Table 4 Continued

Reference	HRQoL measure	Created for Indigenous population	Modified for Indigenous population	Validated for Indigenous population	Reliability in Indigenous population	Indigenous involvement	Refer to Indigenous theories/models/frameworks
Young <i>et al</i> ⁶²	ACHWM	Yes	N/A—created for Indigenous population.	Yes: the content validity of this measure has been established for First Nations, Métis and Inuit children in Canada.	Yes	Coled by a First Nation health director (MJW), had the guidance of a Wiikwemkoong Elder. Study was also approved by the Wiikwemkoong chief and council and the Manitoulin Anishinaabek Research Review Committee.	Based on the Medicine Wheel Framework, which includes questions to assess each of the 4 quadrants (or domains) of health: spiritual, emotional, physical and mental.
Young <i>et al</i> ⁶¹	ACHWM	Yes	N/A—created for Indigenous population.	Yes	Yes	Coled by a First Nation health director (MJW), and also worked in collaboration with other Aboriginal health leaders and Elders.	Based on the Medicine Wheel Framework, which includes questions to assess each of the 4 quadrants (or domains) of health: spiritual, emotional, physical and mental.

ACHWM, Aboriginal Children's Health and Well-being Measure; AQLQ (Juniper's version), Asthma Quality of Life Questionnaire (Juniper's version); AQoL-6D, Assessment of Quality of Life-6 Dimensions; CCOoL, Chronic Cough-specific Quality of Life; CHQ, Child Health Questionnaire; CHQ-PF28, Child Health Questionnaire Parent-Reported Form 28 items; CHU-9D, Child Health Utility-9 Dimensions; COHoL, Child Oral Health Quality of Life Questionnaire; CPQ 11-14, Child Perceptions Questionnaire for children aged 11-14 years; FIS, Fatigue Impact Scale; HRQoL, health-related quality of life; JAQQ, Juvenile Arthritis Quality of Life Questionnaire; OHLIP, Oral Health Impact Profile; OHRQoL, oral health-related quality of life; OM-6, Orits Media-6; PAQLQ, Paediatric Asthma Quality of Life Questionnaire; P-CPQ, Parental-Caregivers Perceptions Questionnaire; PC-QoL, Parent Cough-specific Quality of Life Questionnaire; PedsQL, Paediatric Quality of Life Inventory; PVOS, Paediatric Voice Outcomes Survey; PVRQoL, Paediatric Voice-Related Quality of Life; QoML, Quality of My Life Questionnaire; SEIQoL-DW, Schedule for the Evaluation of Individual Quality of Life-Direct Weighting; SF-6D, Short Form-6 Dimensions; SF-36V2, Short Form-36 Health Survey Questionnaire version 2; SRS-22, Scoliosis Research Society Outcomes Questionnaire-22; VELO, VPI Effects on Life Outcomes; WHO-5, WHO-Five Well-being Index; WHOQOL-BREF, WHO Quality of Life-BREF.

leaders and Elders with the support of the Chiefs of Ontario.^{81–84 87}

The Wicozani Instrument⁶⁷ is a nine-item measure created in response to deficit-focused health outcomes and the need for an easily accessible measure for elders and youth. It includes three dimensions: mental, physical and spiritual health. In Dakota language, wicozani means overall health and well-being, and is grounded in Indigenous paradigms using a strengths-based approach.⁶⁷ The developers note that health is viewed through a holistic lens, and the interconnectedness relationality and interdependency of mental, physical and spiritual aspects of health being recognised. Further, the authors acknowledge that when one aspect of health is affected, all aspects are affected.⁶⁷ The tool includes three written response questions and six questions rated on a 5-point scale. While the authors of this study suggest there is evidence of reliability and validity of the Wicozani Instrument, this is the only paper identified (including grey literature searching) using the Wicozani Instrument; it seems likely that further research is required. Additionally, the Wicozani is not a child/youth-specific measure, though the authors developed the measure with the intent that it be suitable for children/youth.

DISCUSSION

To our knowledge, this is the first scoping (or systematic) review reporting on the use of HRQoL measures in Indigenous child/youth populations. This scoping review also outlines the lack of involvement of Indigenous groups when using many HRQoL measures and the need for culturally founded views of HRQoL and concepts of health to be explored thoroughly.

HRQoL measures are rarely created, adapted, modified, validated or found to be reliable for use in Indigenous populations. There are very few Indigenous-specific HRQoL measures for adults,³⁸ and even fewer suitable for use by children and youth.⁸⁹ To our knowledge, the ACHWM papers^{81–84} are the first to report having created, tested and assessed an Indigenous child/youth HRQoL measure. Further, the ACHWM measure (which was developed specifically for Indigenous children/youth) was found to be valid and reliable by the authors for the Indigenous populations included in their study. Only one study (OPIC study^{55 59 68–70 73}) modified their measure for Indigenous children/youth in their study, either by calibrating or pilot testing the measure. There has been some success in the translation or modification of measures to make them more understandable and culturally appropriate, such as the PedsQL into Tongan,⁷⁰ or modification of examples provided in the Short Form-36 Health Survey Questionnaire version 2 (SF-36v2) questions.⁷⁵ For example, Thomson Mangnall *et al's*⁷⁵ study with Indigenous Fijian participants (aged 12–55 years) substituted the example ‘Moderate activities, such as bowling, vacuuming, playing golf’ for ‘Moderate activities, such as moving a table, sweeping the floor, swimming, or

gardening’.⁷⁵ Written authorisation was obtained for these changes from the SF-36v2 international licencer. However, considerable doubt still remains as to the relevancy of the concepts and dimensions in relation to Indigenous populations.

Relevance of HRQoL health dimensions to Indigenous populations is concerning. A review has reported that economic evaluations of interventions for Indigenous populations often fail to incorporate Indigenous values and conceptions of health into the assessment of benefits.³⁸ Existing HRQoL measures often omit the collective nature in which Indigenous populations view health; for instance, one where family, community, spiritual aspects and connections to the land are imperative for well-being.^{38 67 81–84 87 90} Seven of the identified papers in the scoping review mentioned alternative concepts of Indigenous health (relative to Western conceptions),^{53 67 76 81–84} with five of these using Indigenous-specific measures (the Wicozani Instrument⁶⁷ and the ACHWM^{81–84}). Although the remaining two studies acknowledged alternative concepts of health, no additional dimensions or measures were reported.^{53 76} Further, the majority of papers did not explicitly state whether Indigenous researchers were involved in the study. This signals the need for clearer acknowledgement and/or involvement of Indigenous team members when conducting research with Indigenous population groups.

Only two Indigenous-specific measures were identified. Both included additional concepts of health otherwise not included in other generic HRQoL measures. The ACHWM^{81–84} and the Wicozani Instrument⁶⁷ both included additional concepts of health (such as spiritual health), otherwise not included in generic HRQoL measures. The Wicozani Instrument also acknowledged the impact of colonisation, assimilation and historical trauma on the decimation of native culture and subsequent health and well-being.⁶⁷ If consideration of Indigenous perspectives were implemented from the outset of the design and development of HRQoL measures, more holistic measures that would benefit *all* people would likely be created. That is, the measures may be more applicable to a wider range of populations, not solely Indigenous populations.

Further work is required to determine the appropriateness, acceptability and feasibility of child/youth HRQoL measures for use with Indigenous populations. If such measures are to be used within these populations (and potentially by policy makers and funders to inform decision-making and access to treatments), researchers must determine the cultural relevance and significance of these measures to the Indigenous population within which it is being used. Further, it must be informed by Indigenous worldviews and perspectives on health with respect to broader sociocultural indicators of health that Indigenous populations often bear the burden of. In order to address Article 24 of The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) regarding the equal rights of Indigenous populations to

the highest attainable healthcare, the highest standard of measuring Indigenous health must also be applied. Thus, we strongly recommend the recognition of Indigenous concepts and researchers when developing, validating, assessing and using HRQoL measures with Indigenous populations. Work is currently being done by the research team investigating the concepts of health and well-being important to rangatahi Māori in NZ.

This scoping review had some limitations. First, only papers reporting on Indigenous populations within the Pacific Rim region were included, which may have omitted Indigenous child/youth HRQoL measures from outside this region. Pragmatically, in both size and diversity, a comprehensive review of *all* Indigenous populations globally was deemed beyond the scope of this review. The Pacific Rim is home to the world's most diverse range of Indigenous cultures, many of whom continue to sustain Indigenous ways of life.⁹¹ Second, investigation of HRQoL measures may not have captured wider health and well-being measures (ie, non-HRQoL measures such as flourishing measures⁹²). Third, the scoping review focused on the current *use* of HRQoL measures identified in each paper, therefore did not include investigation of the historical *development* of measures. To this end, involvement of Indigenous populations, theories, frameworks and concepts in the development of measures may have been omitted.

CONCLUSION

There is a clear gap in including HRQoL measures that have been explicitly identified as relevant to Indigenous populations. Consideration of Indigenous health concepts was also not widely considered, nor was there explicit acknowledgement of Indigenous members in research teams.

Culturally founded views of HRQoL and concepts of health need to be explored thoroughly, so that more comprehensive HRQoL measures, aligned to Indigenous concepts of health, can be determined. We strongly recommend the inclusion of Indigenous concepts when developing, validating, assessing and using HRQoL measures with Indigenous populations.

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Contributors GM led the preparation of this paper, drafted the manuscript and led the analyses. GM, EW, TS, SD and SC were involved in the conceptualisation of the scoping review, interpretation of data and finalising the manuscript, and have read and approved the final version. VN independently reviewed at the two screening stages and read and approved the final version. GM is responsible for the over content as guarantor.

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Patient consent for publication Not applicable.

Ethics approval Ethical approval was not required for this scoping review. Dissemination has included a protocol paper previously published in *BMJ Open*. This scoping review informs a larger research project focusing on describing and understanding hauora rangatahi Māori (Māori youth health) in the context of HRQoL measures from the perspectives of rangatahi (young Māori aged 8–17 years) and their whānau (families) (HRC 20/166).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. The data sets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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