

BMJ Open Use of health-related quality-of-life measures for Indigenous child and youth populations: a scoping review protocol

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ABSTRACT

Introduction Measures of health-related quality-of-life (HRQoL) are increasingly important for evaluating healthcare interventions and treatments, understanding the burden of disease, identifying health inequities, allocating health resources and for use in epidemiological studies. Although many HRQoL measures developed for use in adult populations are robust, they are not necessarily designed, or appropriate, to measure HRQoL for children/youth. Furthermore, the appropriateness of HRQoL measures for use with Indigenous child/youth populations has not been closely examined. The aims of this scoping review are to (1) identify and describe empirical studies using HRQoL measures among children/youth (aged 8–17 years) from Indigenous populations within the Pacific Rim, (2) summarise the study designs and modes of HRQoL measure administration, (3) describe the key dimensions of the identified HRQoL measures used among Indigenous populations, including specifically among Māori and (4) map the HRQoL measure dimensions to commonly used Māori models of health.

Methods and analysis The scoping review framework developed by Arksey and O'Malley and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews guidelines will be followed for best practice and reporting. An iterative search of peer-reviewed published empirical research reporting the use of child/youth HRQoL measures among Indigenous populations will be conducted. This literature will be identified across the following five databases: Ovid (Medline), PubMed, Scopus, Web of Science and CINAHL. The search will be restricted to papers published in English between January 1990 and June 2020. Two reviewers will independently review the papers in two stages. A third reviewer will resolve any discrepancies that arise. A data charting form will be completed using data extracted from each paper.

Ethics and dissemination Ethical approval was not required for this scoping review. Dissemination will include publication of the scoping review in a peer-reviewed journal. This scoping review will inform a larger research project (HRC 20/166).

INTRODUCTION

There are approximately 370 million Indigenous people worldwide, belonging to >5000

Strengths and limitations of this study

- This scoping review will identify current knowledge gaps in the literature pertaining to health-related quality-of-life (HRQoL) measures used with Indigenous child/youth populations.
- This scoping review will identify a broad scope of empirical literature pertaining to HRQoL measures used with Indigenous child/youth populations.
- The review will reveal and synthesise the study designs, modes of administration and key dimensions of child/youth HRQoL measures used with Indigenous populations.
- A limitation of this methodology is the lack of quality appraisal associated with a scoping review.
- A further limitation is the exclusion of all non-English papers, which may prevent a number of relevant child/youth HRQoL measures used with Indigenous peoples from being detected.

distinct groups in >90 countries.¹ Although many Indigenous people express similar worldviews and common Indigenous identities, their cultures are based on different histories, environments and spiritualities.² There is no universally accepted, or official, definition of 'Indigenous Peoples'. However, the United Nations has developed factors that have been considered relevant including self-identification as being Indigenous, historically having a precolonial society, strong links to territories and surrounding natural resources, having distinct social, economic or political systems and/or distinct language, culture and beliefs, being in a non-dominant population within a society, and having a resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.¹

Indigenous populations around the world bear increased burdens of disease, disability and mortality compared with non-Indigenous groups.³ This includes poverty, inadequate

healthcare, inadequate health promotion, poor disease prevention and inequities across almost all health conditions.³ Māori, the Indigenous population of Aotearoa (New Zealand), are no exception.^{4 5} Māori experience increased risk, morbidity, disability and mortality due to systematic disparities and unequal access to healthcare services compared with non-Māori.⁴ Such health disparities also extend to rangatahi Māori (Māori children/youth). Among rangatahi Māori, infectious and respiratory diseases, mental illness and common communicable diseases (eg, pertussis, meningococcal and serious skin infections) result in disproportionate hospitalisations, and other poorer outcomes including mortality, relative to non-Māori youth.⁶

An increasingly common approach to measuring health is through the use of health-related quality-of-life (HRQoL) measures.^{7 8} Measures of HRQoL are important for evaluating healthcare interventions and treatments, understanding the burden of disease, identifying health inequities, allocating health resources and for use in epidemiological studies.⁹ HRQoL measures are often used alongside, or instead of, other outcome measures (eg, mortality, hospital admissions and clinical measures).¹⁰ Additionally, in clinical practice, HRQoL measures can help identify and prioritise health treatments for patients, facilitate communication between patients and whānau (family) and healthcare professionals, aid in decision-making and monitoring changes in patients' health.⁹

Economic evaluations using HRQoL data are often integral to healthcare decision-making at population, group and individual levels.⁸ One method commonly used is cost-utility analysis (CUA). In CUA, the costs and benefits of a particular healthcare intervention or service are evaluated and compared with other treatments (or no treatment), with benefits measured according to both the 'quantity' of life (life years) lived in a certain health state, and the 'quality' of that health state measured using certain HRQoL measures.⁸ The product of years of life lived in a certain health state multiplied by the 'value' (ie, utility weight) of that health state is summarised as a quality-adjusted life year.

HRQoL is typically conceptualised as incorporating aspects of health, such as physical and mental health, social functioning and emotional well-being.⁸ HRQoL is a multidimensional concept that encompasses the health-related components affecting quality-of-life, such as physical, mental and emotional health, and social functioning.^{11 12} To measure HRQoL, robust, acceptable and feasible measures are required. Several generic HRQoL measures have been developed for adults such as the EQ-5D,¹³ and Short-Form Six-Dimension (SF-6D),¹⁴ but such measures are not necessarily designed, or appropriate, to measure HRQoL in children/youth. For example, children/youth may have different views about what health comprises compared with adults, and/or may lack some of the vocabulary to discuss their health.^{15 16}

It is important that HRQoL measures for children/youth respond to their developmental, conceptual and

linguistic perspectives and abilities.^{10 17} Some child-specific/youth-specific HRQoL measures have been developed, for example, the Child Health Utility 9D (CHU-9D),¹⁸ the EQ-5D-Y¹⁹ and the Paediatric Quality of Life Inventory (PedsQL).²⁰ The EQ-5D-Y,¹⁹ for example, is a child/youth version of the EQ-5D, intended for the use in children/youth (8–17 years inclusive) and is based on five dimensions: mobility (walking about); looking after myself; usual activities; having pain or discomfort and feeling worried, sad or unhappy. Each dimension is described on three severity levels (eg, 'no/some/a lot' of problems).

As well as having distinct cultures and identities, Indigenous peoples often have differing concepts of health and well-being compared with non-Indigenous groups. Economic evaluations have often failed to incorporate Indigenous values and conceptions of health into the assessment of benefits.²¹ Existing HRQoL measures often limit the focus to narrowly defined indicators of health, disease and associated treatments, to the detriment of considerations of the broader social determinants of health that are particularly important for Indigenous populations. For example, for Māori, health and well-being are holistic concepts and can be demonstrated through Māori models such as Te Whare Tapa Whā,²² Te Wheke²³ and the Meihana model.²⁴ Many components described in these models relate to dimensions that lie beyond the scope of many HRQoL measures such as wairua (spiritual health), whānau (family and community health), identity, connection with the taiao (land and natural environment) and one's relationship and connection with te ao Māori (the Māori world), including to tūpuna (ancestors) and whakapapa (genealogy). Furthermore, Indigenous health models often consider the effects of colonisation, marginalisation, migration and racism.²⁴

Despite increasing interest in the use of HRQoL measures by healthcare funders and agencies, clinicians and researchers, and their use in healthcare decision-making and resource allocation, the appropriateness for use in Indigenous child/youth populations has not been closely examined. It is also unclear which, if any, HRQoL measures have been used, valued, modified or validated for use in Indigenous child/youth populations. In Aotearoa/New Zealand, where various government entities are interested in using evidence from HRQoL assessments to inform their decision-making,^{25 26} it is unclear whether existing HRQoL measures incorporate dimensions of Māori health.

Without investigating whether existing measures are appropriate and acceptable for use with Indigenous children/youth, there is a risk that Indigenous children/youth will be disadvantaged. Therefore, it is vital that Indigenous perspectives are appropriately encapsulated in HRQoL measures in a manner that reflects those aspects of health and well-being that are most important and acceptable for Indigenous youth. It is critical that we explore the ability of 'generic' measures of health for Indigenous youth, and

rangatahi Māori in particular, to more effectively target resources most beneficial to these groups.

Scoping reviews are recommended to examine the extent, range and nature of research activity; to summarise and disseminate research findings and to identify gaps in the existing literature.²⁷ This scoping review will identify and summarise current child/youth HRQoL measures as well as identify gaps in the existing literature regarding their application in Indigenous populations, including specifically for Māori. It will also help identify the HRQoL measures previously/currently used, validated or adapted for the use in Indigenous populations, including specifically for Māori. For the purposes of this article and scoping review, the term ‘child/youth’ refers to those aged 8–17 years, inclusive.

Aims

The aims of this scoping review are to (1) identify and describe empirical studies using HRQoL measures among children/youth (aged 8–17 years) in Indigenous populations within Te Moana-nui-a-Kiwa (the Pacific Rim), (2) summarise the study designs and modes of HRQoL measure administration, (3) describe the key dimensions of the identified HRQoL measures used among Indigenous populations, including specifically among Māori and (4) map the HRQoL measure dimensions to commonly used Māori models of health.

METHODS AND ANALYSIS

This scoping review will be conducted in accordance with the framework developed by Arksey and O’Malley,²⁷ and the subsequent refinements and recommendations made to these methods.^{28–30} There are following six steps in the framework: (1) identifying the research question/s, (2) identifying relevant studies, (3) selecting the studies, (4) charting the data, (5) collating, summarising and reporting the results and (6) consulting with stakeholders to inform or validate study findings (optional). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews³¹ checklist and guidelines will be followed. An iterative process will be applied when defining the research questions, determining relevant studies, selecting studies and charting the data.

Identifying the research questions

The research questions for scoping reviews must necessarily be broad in nature as scoping reviews typically focus on summarising a breadth of evidence.²⁹ Levac *et al*²⁹ recommended that researchers locate their research question, or questions, within a clearly articulated scope of inquiry. This includes defining the concept, target population and the outcomes of interest to clarify the focus of the scoping study and establish an effective search strategy.²⁹ In this review, the scope of inquiry is focused on the ‘concept’ of child/youth HRQoL measures, with the ‘target population’ being Indigenous children/youth

aged 8–17 years, including specifically Māori children/youth aged 8–17 years, and the ‘outcomes of interest’ being evidence of consideration of Indigenous theories, models and frameworks of health in the selection, use and administration of HRQoL measures—including specifically, Māori models of health. The following research questions were formulated based on this scope:

1. Which HRQoL measures are used among Indigenous child/youth populations, including specifically among Māori?
2. What are the components, dimensions and constructs used in the identified child/youth HRQoL measures?
3. Which of the identified papers refer to Indigenous theories, models or frameworks of health when developing and/or using child/youth HRQoL measures?
4. What research designs, HRQoL modes of administration and value sets (if any) have been used in the identified studies using child/youth HRQoL measures?
5. Specifically, to what extent do child/youth HRQoL instruments map to the dimensions of commonly used Māori health models, including Te Whare Tapa Whā,²² Te Wheke²³ and the Meihana model.³²

Identifying relevant studies

Our search strategy was developed with the goal of identifying peer-reviewed published empirical research reporting use of child/youth HRQoL measures among Indigenous populations. In both size and diversity, a comprehensive review of all Indigenous populations globally is beyond the scope of this review. Therefore, we have chosen to focus on Indigenous populations within Te Moana-nui-a-Kiwa (the Pacific Rim), including countries in Micronesia, Polynesia and Melanesia. Firstly, Aotearoa (where the research team is based) is located within Te Moana-nui-a-Kiwa, and has aspects of shared history with many other Indigenous groups in Te Moana-nui-a-Kiwa, such as seafaring ancestors and colonial histories.³³ Secondly, Te Moana-nui-a-Kiwa is home to the world’s most diverse range of Indigenous cultures, many of whom, continue to sustain Indigenous ways of life.³³

An experienced University of Otago subject librarian has been consulted to assist with the development and identification of relevant search terms and databases. An initial search of relevant databases facilitated the identification of empirical literature and determined key words and concepts in the title, abstracts and index terms used. The search strategy has been developed in Medline (Ovid) and will be adapted to other databases (see [table 1](#)). A second search will be conducted using all key words and index terms identified across the following five databases: Ovid (Medline), PubMed, Scopus, Web of Science and CINAHL. The search will be restricted to papers published in English between 1990 and 2020. We have limited the search from 1990 onwards, as HRQoL measures for children were beginning to be developed from the early 90s, with the measures becoming more widely used 1995 onwards.³⁴ All searches will include a combination of search terms, keywords or related terms.

Table 1 Medline (Ovid) search strategy

Line number	Search term entered into Ovid (Medline)	Results
1	QALY.mp	8800
2	Quality adjusted life year*.mp. OR Quality-Adjusted Life Years/	18238
3	Quality of life.mp. or "Quality of Life"/	343367
4	Health related quality of life.mp.	44395
5	HRQoL.mp.	16524
6	disability adjusted life year*.mp.	755
7	DALY.mp.	1838
8	health adjusted life year*.mp.	4
9	HALY.mp.	60
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9	345317
11	Measure*.mp.	3436667
12	Index.mp.	1051742
13	Scale.mp.	729269
14	Instrument.mp.	118115
15	Questionnaire.mp.	407542
16	Tool.mp.	486099
17	Survey.mp.	522964
18	11 or 12 or 13 or 14 or 15 or 16 or 17	5465091
19	Child*.mp.	2429679
20	Adolesc*.mp.	2094396
21	Young adult.mp.	862101
22	Youth.mp.	72474
23	Teen*.mp.	30713
24	Rangatahi.mp.	3
25	Tamariki.mp.	12
26	19 or 20 or 21 or 22 or 23 or 24 or 25	3899562
27	M?ori*.mp.	23575
28	Maori*.mp.	3456
29	Maaori*.mp.	6
30	Pacif*.mp.	41329
31	Pasif*.mp.	0
32	Aborigin*.mp.	9928
33	"first nations".mp.	1373
34	Oceanic ancestry group.mp. or Oceanic Ancestry Group/	10188
35	Indigenous*.mp. or Indigenous Peoples/	34407
36	Melanesia.mp. or Melanesia/	1443
37	Papua New Guinea.mp. or Papua New Guinea/	5337
38	Solomon island*.mp.	854
39	"Santa cruz island*".mp.	90
40	Vanuatu*.mp. or Vanuatu/	708

Continued

Table 1 Continued

Line number	Search term entered into Ovid (Medline)	Results
41	Fiji*.mp. or Fiji/	2330
42	New Caledonia* or New Caledonia/	1742
43	Polynesia.mp. or Polynesia/	2588
44	Hawaii*.mp. or Hawaii/	12755
45	Tuvalu*.mp.	74
46	Tokelau*.mp.	112
47	Samoa*.mp. or Samoa/	1467
48	Tonga*.mp. or Tonga/	720
49	Kermadec island*.mp.	19
50	Cook island*.mp.	270
51	Niue*.mp.	117
52	Society island*.mp.	76
53	Marquesas island*.mp.	60
54	Austral island*.mp.	18
55	Tuamotu*.mp.	55
56	Mangareva island*.mp.	3
57	Gambier island*.mp.	8
58	Easter island*.mp.	211
59	Pitcairn island*.mp.	24
60	Norfolk island*.mp.	71
61	Wallis and Futuna*.mp.	37
62	Rotuma*.mp.	17
63	Kiribati*.mp.	201
64	Tahiti*.mp.	358
65	Micronesia.mp. or Micronesia/	1632
66	Mariana island*.mp.	206
67	Caroline island*.mp.	37
68	Marshall island*.mp.	318
69	Gilbert island*.mp.	19
70	27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69	128920
71	10 and 18 and 26 and 70	253
72	limit 70 to (English language and yr="1990 -Current")	244

Run date=25 June 2020.

Boolean logic and operators (ie, 'AND', 'OR') will be used to combine search terms and concepts. Reference lists of included studies will also be searched for further applicable studies using backwards and forward searching technique.

Study selection

Identified relevant studies from all databases will be exported to Endnote, a data referencing management tool. Duplicates will be identified and deleted using the de-dup function on Endnote and through a manual scan of the reference list.³⁵ A final list of studies will be recorded. The reviewers (GM and one other) will independently review all titles and abstracts using the agreed eligibility criteria, meeting at the beginning, midpoint and final stages of the abstract and title review process. Papers will be included in the full-text review if they meet the following three inclusion criteria: (1) refer to a HRQoL measurement/instrument/ tool/questionnaire/ scale/index/survey, (2) include a measure that is used in any child/youth population aged between 8 and 17 years old and (3) include a measure that is used in any Indigenous population. Where it is unclear from the title and abstract review whether the three inclusion criteria are met, the paper will also proceed to full-text review. The full-text papers selected will be independently reviewed and determined to have met all three inclusion criteria by two researchers (GM and one other). Disagreements will be resolved by consulting a third reviewer (EW) to reach consensus.

Charting the data

The research team (GM, EW, TS, SD and SC) will collectively develop the data-charting form according to the Arksey and O'Malley²⁷ framework. An Excel spreadsheet will be used to record, for example, author(s), year of publication, HRQoL measure, country in which the measure was used, within which age range the measure was used, whose perspective (eg, child or parent), dimensions measured, elicitation technique (eg, time trade-off, standard gamble or Visual Analogue Scale), mode of administration, use in Indigenous populations (including use with Māori participants). Two researchers (GM and EW) will pilot the charting form with the first 5–10 studies to determine whether the approach to data extraction is consistent with the research questions and purpose and that all relevant information is being captured. The researchers will meet at the beginning, midpoint and end to discuss and check alignment and consistency in charting the data. The two researchers (GM and one other) will then independently chart the studies, with a third (EW) resolving any discrepancies that arise.

Collating, summarising and reporting the results

A two-step approach will be implemented to summarise the findings from all included studies. Step 1 will involve a narrative synthesis of the characteristics and findings of the studies. Studies will be organised by the type of HRQoL used with Indigenous populations. For example, whether an HRQoL measure was created for use in Indigenous populations, modified for the use in Indigenous populations, validated for use in Indigenous populations or simply used in a non-tailored way in Indigenous populations. The type of HRQoL measure and its dimensions

of health used in each Indigenous population will also be described. Step 2 will identify the degree to which components of HRQoL measured in the studies align to Indigenous components of health. We will describe any explicit consideration of Indigenous models, frameworks or theories of health reported in the identified studies. Specifically, we are also interested in the extent the HRQoL measures used in Māori populations can be mapped to the dimensions of Māori models of health, such as Te Whare Tapa Whā,²² Te Wheke²³ and the Meihana model.²⁴ A cross-tabulation table will be populated in Excel to demonstrate the correlation between the different dimensions of identified child/youth HRQoL measures and Māori health models.

Consultation process

An external advisory group will be formed during this project to present and discuss the findings of this scoping review, the potential implications and to ensure the findings are relevant to Indigenous populations, and specifically to Māori.

Patient and public involvement

No patient involved.

Ethics and dissemination

Ethical approval for this scoping review was not required. Although child/youth HRQoL measures are increasingly important for healthcare funding and decision-making, it is unclear what and how these measures have been used with Indigenous populations. To our knowledge, our scoping review will be the first to systematically describe the extent and nature of the use of HRQoL measures with Indigenous child/youth populations, including what elements of these measures map to dimensions of Māori health. Therefore, this scoping review is expected to be of interest to key New Zealand organisations (eg, PHARMAC, the Ministry of Health, Accident Compensation Corporation and Māori health providers), as well as internationally given the dearth of literature pertaining to the use of HRQoL measures used with Indigenous populations. Our dissemination strategy will include publication of the scoping review in an open-access peer-reviewed journal as well as presentations at relevant conferences. Findings will also be discussed and interpreted with the external advisory group, ensuring relevance to Māori as well as wider dissemination within these networks. Furthermore, this scoping review will inform a larger research project investigating the acceptability and feasibility of these measures used with rangatahi Māori (HRC 20/166).

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Contributors GM: completed an initial draft of the scoping review protocol and led the development of the research questions and methods. EW, TS, SD and SC: jointly helped conceptualise the scoping review and guided the development of the

research questions and methods, as well as contributed to the writing of multiple drafts of this manuscript.

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Competing interests None declared.

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