Rating Health and Social Indicators for Use with Indigenous Communities: A Tool for Balancing Cultural and Scientific Utility

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Abstract This study reports on the development and evaluation of a rating tool to assess the scientific utility and cultural appropriateness of community-level indicators for application with Indigenous populations. Indicator criteria proposed by the U.S. Institute of Medicine were culturally adapted through reviewing the literature and consultations with academic and Indigenous stakeholders. Pre-testing and collaborator feedback drove the iterative development of the tool with stakeholder groups in Canada, Aotearoa/New Zealand, and Australia. Pilot testing with 17 raters across countries involved rating the same selection of six health and social indicators using a six-point ordinal scale. The final version of the rating tool includes 16 questions within three criterion domains: *importance, soundness*, and *viability*. Academic and community stakeholder review

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established face and content validity. The indicator rating tool demonstrated good internal consistency and excellent inter-rater reliability for two of three pilot testing groups. Use of this instrument can strengthen collaborative research planning and evaluation with Indigenous communities through selection of relevant and culturally appropriate indicators for application to public health research, prevention programmes, and health and social policy.

Keywords Community participation · Health status indicators · Indigenous populations · Reliability and validity · Programme planning

1 Introduction

Indigenous peoples in Canada, Australia, and Aotearoa/New Zealand are profoundly disadvantaged on virtually all markers of health and social status. Despite ongoing efforts to improve Indigenous health, disparities between Indigenous and non-Indigenous populations in these and other western nations continue to grow. Indigenous populations in Canada, Australia, and Aotearoa/New Zealand face significantly higher mortality rates, higher rates of infectious and chronic diseases, poorer overall health status, and life expectancies at birth between 8 and 20 years lower than their non-Indigenous counterparts (Australian Bureau of Statistics, & Australian Institute of Health and Welfare 2003; Ellison-Loschmann and Pearce 2006: Health Canada First Nations and Inuit Health Branch 2003; Martens et al. 2005). In addition to these persistent health disparities, Indigenous populations also face an increasing burden from sexually transmitted infections (Australian Bureau of Statistics. & Australian Institute of Health and Welfare 2003: Health Canada First Nations and Inuit Health Branch 2003), tuberculosis (Das et al. 2006; Dyck et al. 2007; Health Canada First Nations and Inuit Health Branch 2003), epidemics of HIV/AIDS (Guthrie et al. 2000; Health Canada First Nations and Inuit Health Branch 2003) and lifestyle-related diseases, particularly cardiometabolic diseases (Australian Bureau of Statistics, & Australian Institute of Health and Welfare 2003; Riddell 2005; Young et al. 2000).

To more sensitively and effectively respond to Indigenous health needs, there has been a growing shift to the provision of Indigenous community-directed and controlled health and social services, particularly for preventing disease and promoting health. These programmes attempt to account for the cultural, social, economic and historical contexts of Indigenous communities, and to tailor programmes to local cultural and community contexts to facilitate better penetration and uptake of prevention initiatives. Such programmes require data on health and social indicators concerning contextual aspects of community-level environs that influence lifestyle, health risks, and disease outcomes. Selecting indicators that will adequately and appropriately measure these characteristics is challenging, as most such indicators are created by non-Indigenous bodies and therefore may not capture information relevant and meaningful to community prevention efforts.

Many researchers and community stakeholders criticise the application of conventional health and social indicators and highlight the importance of indicators that reflect community goals and social contexts in planning and evaluating community-based prevention efforts (Hancock et al. 1999; Pearce 1996; Walker et al. 2003). Issues of adequacy of existing indicators are especially pertinent when considering their application for research, surveillance, and monitoring prevention programmes in Indigenous communities.

Few indicators incorporate traditional knowledge, cultural and historical issues, or a holistic approach to health—considerations that are essential to health and community development efforts for many Indigenous peoples (Durie 1994; Giles and Findlay 2004; Thompson and Gifford 2000; Wilson and Rosenberg 2002).

The lack of culturally relevant indicators stems from researcher-driven efforts which, albeit well-intended, have not provided adequate opportunities for Indigenous stakeholders to contribute to the research process. Non-participatory approaches to Indigenous community health research are no longer tenable owing to research that is not socially or culturally relevant or provide benefit to Indigenous communities. The importance of community engagement is reflected in ethical guidelines and codes of research ethics for conducting Indigenous health research in Canada (Schnarch 2004), Australia (VicHealth Koori Health Research and Community Development Unit 2000) and New Zealand (Health Research Council of New Zealand 1998). Participatory research has the added benefit of balancing cultural and social relevance with scientific rigour (Fisher and Ball 2005; Daniel et al. 1999); demonstrated benefits to research range from enhanced participant recruitment and retention rates, enhanced cultural validity of measures, reduced reporting bias, enriched interpretation of research findings and increased translation of findings into action (Cargo and Mercer 2008).

Given the need for culturally relevant indicators, community-based endeavours to create and monitor indicators that better address local concerns and contexts have burgeoned since the early 1990s (Besleme et al. 1999; Norris and Pittman 2000). Many examples of Indigenous (Giles and Findlay 2004; Karjala et al. 2004; Steering Committee for the Review of Government Service Provision 2003) and non-Indigenous (Ontario Healthy Communities Coalition 1999; Popovich 1996; Stein 1996; Waddell 1995) community indicator projects demonstrate increased attention to community engagement in multistakeholder processes for indicator development.

Several sets of criteria have been developed to assist policymakers, researchers, and communities to assess indicator validity, reliability, and applicability for different needs. The U.S. Institute of Medicine (IOM) synthesised the selection criteria literature for health quality and population health measures. This work notes that health indicator selection guidelines most often include consideration of indicator relevance, meaningfulness or interpretability, scientific evidence, reliability or reproducibility, feasibility, and health importance (Institute of Medicine, Committee on the National Quality Report on Health Care Delivery 2001).

Given concerns about applying mainstream indicators to the specific contexts of diverse communities including Indigenous populations, alternate criteria have been proposed to inform the planning and evaluation of community-based prevention programmes. Criteria include assessing indicators according to characteristics such as relevance to and accessibility by the community, changeability of conditions by direct citizen or indirect policy change, sensitivity to change over time, and ability to disaggregate data (Black and Hughes 2001; Hancock et al. 1999; Institute of Medicine, Committee on the National Quality Report on Health Care Delivery 2001; Sawicki and Flynn 1996; Waddell 1995). Beyond evaluation criteria, the process by which indicators are evaluated and chosen is vital. In accordance with participatory research principles (Cargo and Mercer 2008), many have called for the inclusion of community representatives in the selection of indicators representing community-level characteristics (Hancock et al. 1999; Karjala et al. 2004; Raphael et al. 1999; Waddell 1995). Several guidelines and toolkits have been created to assist communities in this work (Kingsley 1999; Ontario Healthy Communities Coalition

1999; Redefining Progress, & Earthday Network 2002; Tyler Norris Associates. Redefining Progress, & Sustainable Seattle 1997; U.S. Environmental Protection Agency).

Criteria, guidelines, or a tool for use in and by Indigenous communities to evaluate and select indicators does not exist. This project aimed to develop selection criteria and a rating tool that could be applied by Indigenous community stakeholders, policymakers, health professionals and researchers to assess the utility and appropriateness of existing health and social indicators for use in Indigenous community-based health research and prevention programme planning and evaluation.

2 Methods

2.1 Tool Development

Based on a review of existing criteria we culturally adapted the indicator criteria proposed in the IOM study to be relevant to Indigenous communities. Methodological and quality criteria from other indicator projects and medical, health promotion, and environmental assessment research were also consulted, including considerations of validity, timeliness, sensitivity, comparability and flexibility (Kramers 2003).

The rating tool was developed and refined through a collaborative and iterative process (Fig. 1) that engaged Indigenous and academic stakeholders from Canada, Australia, and Aotearoa/New Zealand.

In its original form the indicator rating tool was comprised of a statement on the intended purpose of the tool and 18 questions within three criteria: *Importance, Soundness,* and *Viability*. A four-point rating scale and a "Not Applicable" option were included on the tool.

To establish the face and content validity of the rating tool, feedback was obtained through:

- Three teleconferences with academic and community partners in the three countries.
- Three discussion groups and four interviews with Indigenous stakeholders (n = 14).
- An international meeting with 14 Indigenous and academic stakeholders from the three countries.



Fig. 1 Community indicator rating tool development process

In response to feedback a slightly revised tool was then submitted for pretesting by Indigenous partners in each country (range 3–4 persons per country). Pre-testers without English literacy limitations indicated that completing the form was straightforward and they believed the tool would be useful for communities that were interested in selecting indicators for programme planning and evaluation uses. Pre-testers with lesser English literacy had some difficulty filling out the form.

Qualitative content analysis indicated five categories of problems encountered by pre-testers:

- 1. Jargon and specific terms that were difficult to understand (e.g., "upstream" influences on health) or that might be understood differently by different individuals (e.g., "at the community level").
- 2. Understanding the intention of some questions within the cultural validity and scientific validity criteria.
- Some questions were not applicable for rating certain indicators and participants were unsure about how to respond. Pre-testers recommended that users be reminded of the "Not Applicable" response option.
- 4. Pre-testers found two questions that incorporated more than one concept and suggested that these ideas be separated into distinct questions.
- Cultural appropriateness was a concern for participants regarding the wording of two questions in the soundness criterion.

Meeting participants commented on the specialised knowledge required to answer questions in the scientific validity sub-domain of the soundness criterion, noting that those without community health research or other professional public health experience would be precluded from completing this section. It also emerged that use of the indicator rating tool was predicated on a willingness to accommodate both scientific and Indigenous perspectives and that those who would be applying the tool should be aware of that before use.

A consensus-based process to revise questions for each criterion was conducted with academic and community-based partners; results are shown in Table 1. Collaborators suggested adding a glossary of key terms. These definitions were developed and included. In addition, the four-point response scale was replaced by a six-point response scale. Further, to maintain a commitment to balancing Indigenous and scientific perspectives, questions concerning scientific validity were separated from other questions into a distinct "Part B" of the form, designated for completion by those with training in scientific methodology.

2.2 Pilot Testing

Pilot testing with the revised criteria and rating tool was conducted with Indigenous community partners in each country. Each pilot testing session in each country was led by a facilitator—a program officer familiar with the tool and the aims of the project. From a sample of indicators used by government statistical agencies in each of the three countries, six indicators for pilot testing were selected (each session rated these six indicators) to represent a variety of domains of community attributes. These domains were based on an conceptual framework and indicator classification system developed as part of the project (Marks et al. 2007).

Criteria	Sub-domains	Items
IMPORTANCE of what is being	1. Importance of what is being measured	(a) Would this indicator be useful for Indigenous people (your community)?
measured		(b) Does this indicator represent a health issue that people consider important?
		(c) Does this indicator reflect an underlying cause affecting Indigenous (or your community's) health?
	2. Indicator changeability	(a) If the condition represented by this indicator changed, would health change?
		(b) Could the condition represented by this indicator be changed at the present time (for example, by implementing policies, programmes, services, or activities)?
SOUNDNESS of what is being	 Indigenous cultural validity 	(a) Is the concept represented by this indicator related to Indigenous knowledge, values, or beliefs?
measured		(b) Should this indicator <u>only</u> be measured by Indigenous researchers?
		(c) Could this indicator be measured by others in partnership with Indigenous researchers?
		(d) Could this indicator be measured respecting Indigenous knowledge, values, and beliefs?
VIABILITY of collecting	4. Indigenous ethical acceptability and appropriateness	(a) Is there any concern about the suitability of collecting data on this indicator?
information on this indicator		(b) Is using this indicator acceptable from an Indigenous ethical perspective?
		(c) Is there any outstanding concern about how the information provided by the indicator will be used?
	. Feasibility of community data collection on this	(a) Is it financially feasible for communities to collect data on this indicator?
	indicator	(b) Could local research capacities provide for systematic collection of data on this indicator?
SOUNDNESS of what is being measured	6. Scientific validity and reliability (to be answered only by those with scientific background)	(a) Is this indicator relevant to different Indigenous populations (including Canada, Australia, and Aotearoa/New Zealand)?
		(b) Do you think this indicator excludes any group that should be included?
		(c) Does this indicator measure the concept that it is supposed to measure?
		(d) Is there evidence to support a link between this indicator and Indigenous health?
		(e) Could this indicator produce similar results under similar circumstances?

 Table 1
 Criteria, sub-domains, and questions contained in indicator rating tool during pilot testing

2.3 Data Analysis and Tool Revision

As response scales for all items were identical, we computed *standardised alphas* (representing consistency among items) and *item-total correlations* (the relation of question scores to total scale scores) to assess the properties of questions in the tool for each indicator rated.

Based on these analyses and a review of comments from facilitators about questions in the tool that presented difficulty to raters, revisions were made. To identify and rectify items that were inconsistent, each domain was examined and problematic items were removed or reworded.

In addition, for each indicator pilot tested, agreement between raters was assessed by country using the *intraclass correlation coefficient* (ICC). Here, the ICC reflects the proportion of the total variance due to the "true" variance among items falling under a given indicator for a given country (a low ICC indicates poor agreement between rater scores for a given indicator). The tool was designed to assess aggregated scores in group rating exercises, rather than individual ratings of indicators. As random errors tied to individual ratings will average out in aggregated scores, we adapted our reliability coefficient to reflect the resulting superior reliability of average scores compared to individual ratings by controlling for the number of individual ratings (i.e., number of raters) on which the average was based (Streiner and Norman 2003). The ICC was calculated as $(\sigma_i^2/(\sigma_i^2 + (\sigma_r^2 + \sigma_e^2)/k))$, where σ_i^2 is the variance component for the items, σ_r^2 is the variance component for the raters, σ_e^2 is the variance component for residual error, and *k* is the number of raters. Guidelines for evaluating ICCs consider values below 0.40 as poor, from 0.40 to 0.59 as fair, from 0.60 to 0.74 as good, and from 0.75 to 1.0 as excellent (Cicchetti 1994).

3 Results

3.1 Pilot Testing

Seventeen individual Indigenous raters primarily involved in community prevention service planning or provision were involved in pilot testing the indicator rating tool. For each indicator, 14–17 participants (6–7 in Aotearoa/New Zealand, 2–5 in Australia, and 5 in Canada) applied the rating tool. Participants were encouraged to participate in the entire rating session, but this was not always possible. In Australia and Aotearoa/New Zealand there was variation in the number of raters for each indicator. Given the flexibility required for participatory research, raters' responses were included in analyses, even if they had not rated all indicators.

Seven participants returned forms with missing data; less than 2.5% of rating responses were missing. Thirty-six of 45 missing responses were for questions within Part B of the form (scientific validity section). Missing values were substituted for the question for that indicator using mean values for responses for that country. There were no "Not Applicable" responses to any questions for any indicators.

Twelve items in the tool had an item-total correlation <0.2 in analysis of the full scale for at least one indicator (Table 2). Of these, five items had item-total correlations <0.2 for the full scale in \geq 50% of the indicators rated. Three of these items (3b, 6a, 6b) were removed; for two of these items (4a and 4c) the wording of questions was revised. Responses to items 4a and 4c which asked about "any concern" were almost uniformly high. Item 3b was removed, as it likely reflected raters' political or personal opinions, rather than any true perspective on the indicator in question. Item 6a was removed as the tool's purpose had broadened to allow raters to answer questions from the perspective of their community. Item 6b was removed because participants found the question and the concept it was addressing to be confusing.

Criteria	Sub-domain	Items	Number of indicators for which item-total correlation <0.2
IMPORTANCE of what is	Importance of what is being	1a	0
being measured	measured	1b	0
		1c	1
	Indicator changeability	2a	1
		2b	0
SOUNDNESS of what is	Indigenous cultural validity	3a	2
being measured		3b*	5
		3c	2
		3d	2
VIABILITY of collecting	Indigenous ethical acceptability and appropriateness	$4a^*$	6
information on this indicator		4b	2
		$4c^*$	5
	Feasibility of community data	5a	1
	collection on this indicator	5b	2
SOUNDNESS of what is	Scientific validity and reliability	6a [*]	3
being measured		6b [*]	4
		6c	2
		6d	1
		6e	0

Table 2 Items with low item-total correlations in indicator rating tool pilot testing (across all participants) (n = 6 indicators)

* Items with low item-total correlations for at least 50% of indicators rated. These five items were either removed from or reworded in the final version of the instrument

For the 14 questions retained unedited in the tool, individual participants' ratings of indicators ranged from 14 to 62 out of a possible range of scores of 14 (all questions answered most positively) to 84 (all questions answered most negatively). Mean summary scores for rated indicators ranged from 25.9 (SD = 2.8) to 52.6 (SD = 10.8) for Australian participants; 20.0 (SD = 3.5) to 24.6 (SD = 7.2) for Canadian raters; and 22.7 (SD = 4.1) to 27.7 (SD = 8.2) for Aotearoa/New Zealand pilot testers. Across all pilot testing sessions, the mean rating for all seven indicators was 27.3 (SD = 9.7).

Table 3 shows the internal consistency for these 14 unedited items as ranging from 0.65 to 0.95 for the six indicators rated. Alpha values of 0.70 or greater are widely interpreted as acceptable (Streiner and Norman 2003). Average item-total correlations ranged from 0.24 to 0.75. Ratings of the "removed or separated from family during childhood" indicator yielded the lowest internal consistency for all measures. Supplementary analyses of data on this indicator excluding raters from Aotearoa/New Zealand, where forced removal of children to church- or state-run institutions or placement with white families was not practised to same extent as in Australia and Canada (Armitage 1995), yielded a standardised alpha of 0.76 and an average item-total correlation of 0.33 (Table 3).

Inter-rater reliability calculations for all items in the pilot-test version of the tool demonstrated excellent agreement for all indicators for raters in Aotearoa/New Zealand (ICC range: 0.83–0.93) and Canada (ICC range: 0.82–0.96) (Table 3). Inter-rater reliability

Indicator		Avg. item-total correlation	Standardised alpha
1.	Percent of community residents who report hunting, fishing, or gathering wild plants in the past 12 months	0.75	0.95
2a.	Percent of residents who were removed or separated from their families for any length of time during their childhood	0.24	0.65
2b.	Percent of residents who were removed or separated from their families for any length of time during their childhood*	0.33	0.76
3.	Average amount of time individuals engage in recreational gambling in a typical week	0.37	0.76
4.	Community is involved in self-government negotiations	0.53	0.87
5.	Percent of households that report running out of money for food is a problem	0.43	0.81
6.	Community accessible by road year round, with no road closures for considerable amounts of time	0.48	0.84
All	indicators	0.52	0.86

 Table 3
 Internal consistency for indicator rating tool for all items retained in the final instrument, across all raters in all countries, by sample indicator rated

* Excluding Aotearoa/New Zealand raters' responses

of Australian participants was excellent for two indicators, good for one indicator, fair for one indicator, and poor for two indicators. ICC values ranged from 0.00 to 0.79 for the Australian raters. Across the three countries, ICC values showed excellent agreement, ranging from 0.88 to 0.95.

3.2 Final Instrument

Based on the pilot testing results, the rating tool was revised. Appendix 1 shows the final, formatted instrument. Items 4a and 4c were re-worded in more neutral language to reduce skewness of responses. The "Not Applicable" response option was retained, even though no pilot testing raters had selected it. The final 16-item instrument was comprised of 14 unedited items and two edited (re-worded) items.

4 Discussion

Overall, the indicator rating tool pilot tested in this study demonstrated good reliability, except for application to one indicator of little relevance to participants in Aotearoa/ New Zealand. The iterative development process resulted in an instrument with 16 questions within three domains and six sub-domains. Pilot test ratings of indicators were positive overall, though mean summary scores for Australian participants were higher (more negative) for all indicators. Questions retained in the tool demonstrated good internal consistency. Inter-rater reliability was excellent for all indicators for two of three pilot testing groups; agreement of raters in Australia was less consistent, but fewer raters and a more variable group of participants could explain this discrepancy. Lower reliability results may reflect greater rater heterogeneity among Australian raters: participants represented a broad range of sectors (health, sport, education, language, and government), urban and rural areas.

Face validity (where the instrument appears to measure what it purports to measure) and content validity (where the items in the instrument are sufficiently representative of the content domains being measured) were established by consultation with stakeholders and collaborators in teleconferences and meetings. Participants in the iterative development process (Fig. 1) and the consensus-based tool revision process explicitly addressed content and face validity in their meetings.

This tool enables systematic evaluation of the utility of *existing* indicators. In so doing it might become apparent that existing indicators do not extend to areas of concern to Indigenous people, *such as* constructs including strength of cultural identity, loss of land or traditional ties to land or one's people, systemic racism and other aspects of relations with mainstream cultures, or capability in tapping the circumstances of different settings (e.g., urban vs. remote). Such determinations may suggest a need for developing new indicators, where the tool could again be applied to select newly developed indicators evaluated against criteria of scientific validity and cultural relevance.

Our tool is not intended to replace procedures for validating newly developed indicators, or to serve to identify constructs or content areas for which new indicators are needed. Its purpose is to guide assessment of the appropriateness of proposed indicators selected by a range of user groups including policy-makers, program managers, and prevention researchers. For this purpose we contend, on the basis of our reliability and validity testing results, that the tool is of sound construction and relevant to academic-scientific prevention partnerships with Indigenous communities, where a balance of scientific and cultural utility is desirable (Cargo et al. 2007).

This study has several limitations. Given participants' time constraints, the tool was pilot tested with a limited pool of indicators, and we could not assess a selection of "good" and "bad" indicators to assess the discriminative validity of the tool as when testing a clinical diagnostic instrument. Also, as the tool was designed as part of an international collaborative health research programme involving participants in Australia, Canada, and Aotearoa/New Zealand, the generalisability of the instrument to other populations, or for use in other types of projects, is unknown. Further, we assessed the reliability of the instrument for a mix of people from Indigenous bodies and governmental organisations representing a range of backgrounds and prior experiences. Future studies may wish to examine how the psychometric properties reported here might vary according to the characteristics of raters (e.g., different ratings by Indigenous living in urban vs. non-urban or remote environments).

Future needs include retesting reliability and further validity evaluations after further testing of the final revised version of the instrument. As the pre-testing and pilot testing utilised indicators from a range of conceptual domains, additional testing should also assess the ability of the tool to discriminate between indicators that represent the same or a similar construct. Feedback from communities applying the tool will provide essential information to guide its dissemination and any necessary subsequent revisions.

The rating tool responds to the increasing trend of collecting data on health and social indicators for public health surveillance, health needs assessment, programme evaluation, and health research activities. But for indicators to be useful for prevention research, they must not only be valid and reliable measures, but also be relevant and appropriate to the specific contexts in which they are being applied. This is particularly true for the use of indicators in programmes with Indigenous communities, where many have noted the challenges to application of existing indicators designed for use in other contexts (Giles and Findlay 2004; Karjala et al. 2004; Ten Fingers 2005; Walker et al. 2002).

Ethics guidelines on conducting research with and in Indigenous communities emphasise the importance of participation of Indigenous community members at all stages of the research process, including determination of the methodology to be employed (Maori Health Committee of the Health Research Council of New Zealand 1998; Medical Research Council of Canada. Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada 2003; National Health & Medical Research Council 2003). Furthermore, involving community stake-holders in indicator selection processes aligns with the principles of participatory research (Cargo and Mercer 2008).

More often seen in other fields such as natural resource management, environmental impact assessment, and sustainable development, indicators based on traditional ecological knowledge and community-based participatory processes for selecting indicators have been advocated and increasingly employed (Karjala et al. 2004; Natcher and Hickey 2002; Reed and Dougill 2002). Other researchers have noted the importance of community involvement for more than mere approval of a list of indicators, but through participation in identifying indicators (Cunningham and Beneforti 2005; Karjala and Dewhurst 2003) and defining appropriate categorizations of indicators (Andersen and Poppel 2002; Natcher and Hickey 2002). Moreover, utilising more meaningful measures and methodologies is essential to addressing concerns that health research is not amply meeting the needs of Indigenous communities (Baum et al. 2006; Smith 1999).

This tool is unique in providing a guided process that balances scientific and cultural concerns whereby health researchers, community members, and public health funding agencies can identify the most relevant indicators to evaluate the effectiveness of Indigenous community-based prevention efforts. Extensive consultation and field testing results support its applicability for health research with Indigenous communities.

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Appendix 1

Final indicator rating tool

Indicator Rating Form

Indicator Name:		Indicator Code:
Date:	Location:	Rater Code:

This form is to assess indicators that might be useful for describing Indigenous communities. Use the form to rate how useful, meaningful and representative indicators are.

PART A of the form is intended for completion by Indigenous peoples, community organisations and health researchers.

PART B of the form is intended for completion by health research funding agencies and Indigenous people with scientific training and/or expertise in Indigenous health research.

PART A: For completion by Indigenous peoples, community organisations and health researchers

IMPORTANCE of what is being measured

1. Meaning of this indicator to communities

a) Would this indicator be useful for Indigenous people (or your community)?

	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	-0	O	—O—	—0	Ø
b)	Does this ind	licator represe	nt a health issu	ue that people c	onsider importa	nt?	
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	O	O	-0	—O	Ø
c)	Does this ind	licator reflect a	n underlying c	ause affecting l	ndigenous (or ye	our community'	s) health?
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	-0	O	-0	—0	Ø
2.	Indicator c	hangeability					
a)	If the conditiv						
)		on represented	by this indicat	tor changed, wo	uld health chan	ge?	
)	Definitely	on represented Probably	by this indicat Maybe	tor changed, wo Maybe not	uld health chan Probably not	ge? Definitely not	Not applicable
)	Definitely	Probably	by this indica Maybe	tor changed, wo Maybe not	uld health chan Probably not	ge? Definitely not	Not applicable
b)	Could the co	Probably Probably O ndition represe g policies, prog	by this indicat Maybe	tor changed, wo Maybe not O Indicator be chan ices or activities	uld health chan Probably not ged at the prese)?	ge? Definitely not	Not applicable
b)	Could the co implementing	Probably 	by this indicat Maybe ented by this in rammes, serve Maybe	tor changed, wo Maybe not dicator be chan ices or activities Maybe not	uld health chan Probably not ged at the press)? Probably not	ge? Definitely not	Not applicable Ø ample, by Not applicable

sc	SOUNDNESS of what is being measured						
3.	Indigenous cultural validity						
a)	Is the concept represented by this indicator related to Indigenous knowledge, values or beliefs?						celiefs?
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	-0	-0	-0	—0	Ø
b)	Could this ind	licator be meas	sured by others	s in partnership	with Indigenou	s researchers?	
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	-0	-0	-0	—O	Ø
c)	Could this ind	licator be meas	sured respectir	ng Indigenous k	nowledge, valu	es, and beliefs	?
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	-0	-0	-0	—0	Ø
vi		oollooting ir	formation	on this india	otor		
V I.			ntohility and				
4.	le thore strop		ut the suitabilit	v of collecting d	leta on this indi	astor?	
a)	IS THEFE SHOT	g concern abou		y of collecting o		Salur ?	
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	_0	-0	-0	_0	—0	Ø
b)	Is using this in	ndicator accept	able from an I	ndigenous ethi	cal perspective?	?	
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	-0	—O—	—O—	—O	Ø
c)	Is there significant reason to be concerned about how the information provided by the indicator will be used?					dicator will	
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	-0	—O—	—O—	—0	Ø
5	Feasibility (of community	/ data collec	tion on this i	ndicator		
a)	ls it financially	v feasible for co	ommunities to	collect data on	this indicator?		
u)	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	\cup –	\cup –	0 -	0 -	\cup –	\cup	×
b)	Could local ca	apacities enabl	e or provide fo	or systematic co	ellection of data	on this indicato	r?
	Definitely	Probably	Maybe	Maybe not	Probably not	Definitely not	Not applicable
	0	-0	-0	—O—	—O—	———————————————————————————————————————	Ø

PART B: For completion by health research funding agencies or Indigenous people with scientific training and/or expertise in Indigenous health research

SOUNDNESS of what is being measured

6. Scientific validity and reliability

a) Does this indicator measure the concept that it is supposed to measure?



References

- Andersen, T., & Poppel, B. (2002). Living conditions in the Arctic. Social Indicators Research, 58, 191–216. doi:10.1023/A:1015787901370.
- Armitage, A. (1995). Comparing the policy of aboriginal assimilation: Australia, Canada, and New Zealand. Vancouver: UBC Press.
- Australian Bureau of Statistics, & Australian Institute of Health and Welfare. (2003). The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples, 2003. Canberra: Australian Bureau of Statistics.
- Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. Journal of Epidemiology and Community Health, 60, 854–857. doi:10.1136/jech.2004.028662.
- Besleme, K., Maser, E., & Sliverstein, J. (1999). A community indicators case study: addressing the quality of life in two communities. San Francisco: Redefining Progress.
- Black, A., & Hughes, P. (2001). The identification and analysis of indicators of community strength and outcomes. Canberra: Department of Family and Community Services, Commonwealth of Australia.
- Cargo, M., & Mercer, S. (2008). The value and challenges of participatory research in public health: strengthening its practice. *Annual Review of Public Health*, 29, 325–350. doi:10.1146/annurev. publhealth.29.091307.083824.
- Cargo, M., Petersen, L., Levesque, L., & Macaulay, A. (2007). Physical activity and perceived wholistic health in indigenous youth. *Pimitziwin*, 5, 87–109.
- Cicchetti, D. V. (1994). Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. *Psychological Assessment*, 6, 284–290. doi:10.1037/1040-3590. 6.4.284.
- Cunningham, J., & Beneforti, M. (2005). Investigating indicators for measuring the health and social impact of sport and recreation programs in Australian indigenous communities. *International Review for the Sociology of Sport, 40*, 89–98. doi:10.1177/1012690205052170.
- Daniel, M., Green, L. W., Marion, S. A., Gamble, D., Herbert, C. P., et al. (1999). Effectiveness of community-directed diabetes prevention and control in a rural Aboriginal population in British Columbia, Canada. Social Science and Medicine, 48, 815–832. doi:10.1016/S0277-9536(98)00403-1.
- Das, D., Baker, M., & Calder, L. (2006). Tuberculosis epidemiology in New Zealand: 1995–2004. The New Zealand Medical Journal, 119, 2249–2264.
- Durie, M. (1994). Whaiora: Maori health development. Auckland: Oxford University Press.
- Dyck, R. F., Klomp, H., Marciniuk, D. D., Tan, L., Stang, M. R., Ward, H. A., et al. (2007). The relationship between diabetes and tuberculosis in Saskatchewan: comparison of Registered Indians and other

Springer

Saskatchewan people. Canadian Journal of Public Health. Revue Canadienne de Sante Publique, 98, 55–59.

- Ellison-Loschmann, L., & Pearce, N. (2006). Improving access to health care among New Zealand's Maori population. American Journal of Public Health, 96, 612–617. doi:10.2105/AJPH.2005.070680.
- Fisher, P. A., & Ball, T. J. (2005). Balancing empiricism and local cultural knowledge in the design of prevention research. *Journal of Urban Health*, 82, iii44–iii55. doi:10.1093/jurban/jti063.
- Giles, B. G., & Findlay, C. S. (2004). *Diabetes indicators for Aboriginal communities: final report*. Ottawa: Institute of the Environment.
- Guthrie, J. A., Dore, G. J., McDonald, A. M., & Kaldor, J. M. (2000). HIV and AIDS in aboriginal and Torres Strait Islander Australians: 1992–1998. The National HIV Surveillance Committee. *The Medical Journal of Australia*, 172, 266–269.
- Hancock, T., Labonte, R., & Edwards, R. (1999). Indicators that count! Measuring population health at the community level. *Canadian Journal of Public Health. Revue Canadienne de Sante Publique*, 90(suppl. 1), S22–S26.
- Health Canada First Nations and Inuit Health Branch. (2003). Statistical profile on the health of First Nations in Canada. Ottawa: Health Canada.
- Health Research Council of New Zealand. (1998). Guidelines for researchers on health research involving Maori. Auckland: Health Research Council.
- Institute of Medicine, Committee on the National Quality Report on Health Care Delivery. (2001). Envisioning the national health care quality report. Washington DC: National Academies Press.
- Karjala, M. K., & Dewhurst, S. M. (2003). Including aboriginal issues in forest planning: a case study in central interior British Columbia, Canada. *Landscape and Urban Planning*, 64, 1–17. doi:10.1016/ S0169-2046(02)00196-2.
- Karjala, M. K., Sherry, E. E., & Dewhurst, S. M. (2004). Critieria and indicators for sustainable forest planning: a framework for recording Aboriginal resource and social values. *Forest Policy and Economics*, 6, 95–110. doi:10.1016/S1389-9341(02)00117-X.
- Kingsley, T. (1999). Building and operating neighborhood indicator systems: a guidebook. Washington DC: The Urban Institute.
- Kramers, P. G. (2003). The ECHI project: health indicators for the European community. *European Journal of Public Health*, 13, 101–106. doi:10.1093/eurpub/13.suppl_1.101.
- Maori Health Committee of the Health Research Council of New Zealand. (1998). Guidelines for researchers on health research involving Maori, 1998. Auckland: HRCNZ.
- Marks, E., Cargo, M. D., & Daniel, M. (2007). Constructing a health and social indicator framework for Indigenous community health research. *Social Indicators Research*, 82, 93–110. doi:10.1007/s11205-006-9016-z.
- Martens, P. J., Sanderson, D., & Jebamani, L. S. (2005). Mortality comparisons of First Nations to all other Manitobans: a provincial population-based look at health inequalities by region and gender. *Canadian Journal of Public Health. Revue Canadienne de Sante Publique, 96*, S33.
- Medical Research Council of Canada. Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2003). *Tri-Council policy statement: ethical conduct for research involving humans. Section 6. Research involving Aboriginal peoples.* Ottawa: Public Works and Government Services Canada.
- Natcher, D. C., & Hickey, C. G. (2002). Putting the community back into community-based resource management: a criteria and indicators approach to sustainability. *Human Organization*, 61, 350–363.
- National Health & Medical Research Council. (2003). Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research. Canberra: Commonwealth of Australia.
- Norris, T., & Pittman, M. (2000). The healthy communities movement and the coalition for healthier cities and communities. *Public Health Reports*, 115, 118–124. doi:10.1093/phr/115.2.118.
- Ontario Healthy Communities Coalition. (1999). Pathways to a healthy community: an indicators and evaluation tool kit. Toronto: Ontario Healthy Communities Coalition.
- Pearce, N. (1996). Traditional epidemiology, modern epidemiology, and public health. American Journal of Public Health, 86, 678–683.
- Popovich, M. G. (1996). Toward results-oriented intergovernmental systems: an historical look at the development of the Oregon Benchmarks. Washington DC: The Alliance for Redesigning Government of the National Academy of Public Administration.
- Raphael, D., Steinmetz, B., Renwick, R., Rootman, I., Brown, I., Sehdev, H., et al. (1999). The community quality of life project: a health promotion approach to understanding communities. *Health Promotion International*, 14, 197–210. doi:10.1093/heapro/14.3.197.
- Redefining Progress, & Earthday Network. (2002). Sustainability starts in your community: a community indicators guide. Oakland: Redefining Progress.

- Reed, M. S., & Dougill, A. J. (2002). Participatory selection process for indicators of rangeland condition in the Kalahari. *The Geographical Journal*, 168, 224–234. doi:10.1111/1475-4959.00050.
- Riddell, T. (2005). Heart failure hospitalisations and deaths in New Zealand: patterns by deprivation and ethnicity. *The New Zealand Medical Journal*, 118, 1254–1264.
- Sawicki, D. S., & Flynn, P. (1996). Neighborhood indicators: a review of the literature and an assessment of conceptual and methodological issues. *Journal of the American Planning Association. American Planning Association*, 62, 165–183. doi:10.1080/01944369608975683.
- Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) of self-determination applied to research. A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, 1, 80–95.
- Smith, L. T. (1999). Decolonizing methodologies: research and Indigenous peoples. New York: Zed Books.
- Steering Committee for the Review of Government Service Provision. (2003). Overcoming Indigenous disadvantage: key indicators, 2003. Canberra: Productivity Commission.
- Stein, B. (1996). The Oregon Benchmarks experience. In Canadian Council on Social Development (Ed.), Measuring Well-Being: Proceedings from a Symposium on Social Indicators: Final Report. Ottawa: CCSD.
- Streiner, D. L., & Norman, G. R. (2003). Health measurement scales: a practical guide to their development and use (3rd ed.). Oxford: Oxford University Press.
- Ten Fingers, K. (2005). Rejecting, revitalizing, and reclaiming: First Nations work to set the direction of research and policy development. *Canadian Journal of Public Health. Revue Canadianne de Sante Publique*, 96(suppl. 1), S60–S63.
- Thompson, S. J., & Gifford, S. M. (2000). Trying to keep a balance: the meaning of health and diabetes in an urban Aboriginal community. *Social Science and Medicine*, 51, 1457–1472. doi:10.1016/S0277-9536(00)00046-0.
- Tyler Norris Associates. Redefining Progress, & Sustainable Seattle. (1997). *The community indicators handbook: measuring progress toward healthy and sustainable communities*. Oakland: Redefining Progress.
- U.S. Environmental Protection Agency. Green communities. Retrieved June 2007, from http://www.epa.gov/greenkit/index.htm.
- VicHealth Koori Health Research and Community Development Unit. (2000). We don't like research. But in Koori hands it could make a difference. Melbourne: Victoria.
- Waddell, S. (1995). Lessons from the healthy cities movement for social indicator development. Social Indicators Research, 34, 213–235. doi:10.1007/BF01079197.
- Walker, R., Ballard, J., & Taylor, C. (2002). Investigating appropriate evaluation methods and indicators for Indigenous housing programs. Melbourne: Australian Housing and Urban Research Institute.
- Walker, R., Ballard, J., & Taylor, C. (2003). Developing paradigms and discourses to establish more appropriate evaluation frameworks and indicators for housing programs. Melbourne: Australian Housing and Urban Research Institute.
- Wilson, K., & Rosenberg, M. W. (2002). Exploring the determinants of health for First Nations peoples in Canada: can existing frameworks accommodate traditional activities? *Social Science and Medicine*, 55, 2017–2031. doi:10.1016/S0277-9536(01)00342-2.
- Young, T. K., Reading, J., Elias, B., & O'Neil, J. D. (2000). Type 2 diabetes mellitus in Canada's First Nations: status of an epidemic in progress. *Canadian Medical Association Journal*, 163, 561–566.