

Inventory of Patient-Reported Outcome and Experience Measures (PROMs & PREMs) for Indigenous Peoples

Please note that the term “Indigenous” is used, as defined by the United Nations (2007), except in instances where the terms “Aboriginal”, “First Nations”, “Native”, “American Indian” or other Indigenous population related terms (e.g., Māori) are used in the original source.

This inventory was developed on the ancestral and unceded lands of the x̱m̱əθḵəy̱əm (Musqueam), Sḵwx̱w̱ú7mesh (Squamish), and səliiḻwətaʔṯ (Tsleil-Waututh) First Nations, in Vancouver, B.C., as part of the research project, “Pathways for Developing Patient-Reported Outcome and Experience Measures.” This research was a joint project between the University of British Columbia and the BC Children’s and BC Women’s Hospital and Health Centres (C&W)’s Indigenous Health Program and funded by the BC Support Unit.


The instruments in this inventory were drawn from a systematic review of studies with Indigenous population in Canada, Australia, New Zealand and the United States (CANZUS nations). The following electronic databases were searched: MEDLINE(OVID), CINAHL, Psych INFO, Google and Google Scholar. Related websites were also manually searched to find tools that were not published in electronic databases. The measurement instruments reported in this inventory were located in publications that aimed to either develop or adapt Indigenous specific tools in the CANZUS nations. Please note that the methodology of the literature review is presented in detail in a scoping review manuscript currently under development.

Scope of systematic review:

- Patient-reported outcome measures (PROMs) and Patient-reported experience measures (PREMs) developed or adapted (modified for use) for Indigenous peoples in Canada, United States, Australia and New Zealand.
- Used the United Nations (UN) definition of Indigenous peoples to guide this review (<https://www.un.org/development/desa/indigenoupeoples/about-us.html>). However, all Indigenous population related terms (e.g., Aboriginal, Native American, etc.) were used to search for studies on the study population.
- Defined the term “health outcome” using a social determinant lens and consistent with how health/wellbeing is conceptualized in Indigenous cultures; namely, culture is key to health and healing. As such, many studies related to survey tools that at first glance may not have been viewed as PROMs (such as tools that measure identity and cultural engagement) were included in the review.
- In the search some population-based PROMs and PREMs were identified– these were included as they provides valuable insights on potential indicators to measures.
- Targets of PROMs and PREMs: Patients, parents/guardians or caretakers of patients, and/or individuals in the community who are not labeled as patients.

Although Psychometric properties of tools (reliability/validity) are listed in this inventory when available, quality of tools are not assessed on these criteria. Given the scarcity of Indigenous-specific tools and that this field of study is relatively new, “grading” these tools would be inappropriate. The value of each tool lies in demonstrating the possibilities and providing lessons on how to develop, validate and further refine patient-reported outcome and experience measurement tools for Indigenous peoples.

The survey tools presented in this inventory were each developed for a particular Indigenous cultural group. These tools should get validated prior to use for specific Indigenous communities.



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Developed Tools (Designed Specifically For Indigenous Peoples)						
#	Instrument	Construct Measured	Population	Application	Indigenous Lens/ Knowledge or Cultural/Theoretical Frameworks Used in Content Development	Description & Reliability/ Validity
Patient-Reported Outcome Measures (PROMs)						
1.	Aboriginal Children's Health and Well-being Measure, (ACHWM) (Young et al., 2013, 2015, 2015, 2016, 2017)	Holistic health of Aboriginal Children (PROM)	Canada: Aboriginal (Anishinaabek) children/youth (8 to 18 years of age) in North Eastern Ontario	Assess health of children and evaluate improvements over time; to assist in the planning and evaluation of health services	<ul style="list-style-type: none"> - Anishinaabek conceptualization of health: Medicine Wheel framework with health domains of spiritual, emotional, physical and mental. - Full spectrum of health from wellness to illness/Anishinaabek view of balance. 	<ul style="list-style-type: none"> - 62 –item questionnaire (latest version) - ✓ Face and content validity - ✓ Concurrent validity - ✓ Test-re-test reliability - Reliability: Excellent
2.	American Indian Enculturation Scale (AIES) (Winderowd et al., 2008)	Enculturation: the process by which one learns about and identifies with one's cultural roots particularly tribal activities and spiritual practices (degree of involvement in traditional/ cultural ways) (PROM)	United States: American Indians from Oklahoma and Southwestern tribes; both patient and non-patient groups	Developed to be used in counseling practice to assess the enculturation of American Indian (AI) people; to assess cultural engagement in community	<ul style="list-style-type: none"> - Holism: Relates to harmony, balance, connectedness, and wellness. - Traditional ways of knowing and being have protective factors and promotes resilience – essential for harmony and spirit of tribal people. 	<ul style="list-style-type: none"> - 17- item questionnaire - Structure: 1 scale/factor - ✓ Content validity - ✓ Construct validity - ✓ Convergent and discriminant validity - Reliability: Excellent
3.	Awareness of Connectedness Scale (ACS) (Mohatt et al., 2011)	Awareness of connectedness (PROM)	United States: Alaska Native (mainly Yup'ik) Youth	Outcome measure for behavioral health programs	<ul style="list-style-type: none"> - Connectedness is interrelated welfare of the individual, one's family, one's community and one's natural environment – "all of my relatives" - Holistic - "life-world." - Medicine wheel; Balance between the domains of wellbeing. - Strength-based approach: Focus on sobriety, wellness and resilience. - Connectedness as a culturally-based protective factor against substance abuse and suicide. 	<ul style="list-style-type: none"> - 12-item questionnaire (final version). - Structure: 4 subscales/ factors: Individual; Family; Community; Natural Environment - ✓ Convergent validity - Reliability: Good internal consistency for overall scale; good to poor for subscales
4.	Cherokee Self-Reliance Questionnaire	Self-reliance: being responsible, being disciplined and being confident	United States: Cherokee adolescents (developed for males, but used on females in other studies)	Assess impact of interventions	<ul style="list-style-type: none"> - Self-reliance is a concept within the Cherokee holistic worldview where all things are believed to come together to form a whole. 	<ul style="list-style-type: none"> - 24-item questionnaire - Structure: 3 subscales/ factors: Being responsible; Being disciplined; Being confident - ✓ Construct validity

	(Lowe, 2003, 2008; Lowe et al., 2009)	(PROM)			<ul style="list-style-type: none"> - Self-reliance as mainstay and way of life to keep Cherokees in balance. - Cultural themes of being true to oneself and being connected cut across all three qualities of self-reliance (being responsible, being disciplined and being confident). 	<ul style="list-style-type: none"> - Reliability: Good
5.	Cultural Connectedness Scale (CCS) (Snowshoe et al., 2015)	Cultural Connectedness: The extent to which an Indigenous youth is integrated within their culture (PROM)	Canada: First Nations, Métis and Inuit youth (grades 8 to 12) from Urban and rural Saskatchewan and Southwestern Ontario	Assess the impact of cultural preservation programming	<ul style="list-style-type: none"> - Strength-based approach: Culture as having protective factors. - Resilience framework: Natural human capacity to live life well. 	<ul style="list-style-type: none"> - 29-item questionnaire. - Structure: 3 subscales/ factors: Cultural Identity; Traditions; Spirituality - ✓ Content and face validity - ✓ Predictive validity - Reliability: Good to acceptable.
6.	First Nations Children Wellbeing Measure (FNCWM) (Drawson, 2018)	Wellbeing of First Nations Children (PROM)	Canada: First Nations children in the Robinson Superior Treaty Area; Anishinabek children	Assess wellness in Anishinabek children to determine when children are thriving or need additional supports	<ul style="list-style-type: none"> - Embraced the importance of engagement in traditional activities and the role of culture in children's wellbeing. - Importance of relational wellbeing (as opposed to autonomy). - Balanced view: Medicine wheel served as the framework for wellbeing/health; being unwell means being out of balance - First Nations Mental Wellness Continuum Framework: wellness is brought about by balance across a variety of domains and manifests in hope, meaning, belonging, and purpose. - Strength-based: Focused on stories of success when developing definitions and indicators of wellness. 	<ul style="list-style-type: none"> - 51- item questionnaire - Structure: 3 subscale/factors: General well-being; Traditional activities; Social engagement - ✓ Content validity - ✓ Convergent validity - Reliability: Excellent to acceptable
7.	Growth + Empowerment Measure (GME) (Haswell et al., 2010)	Emotional and functional aspects of Empowerment (PROM)	Australia: Aboriginal, Torres Strait Islander	Measure outcomes of a Family Wellness workshop	<ul style="list-style-type: none"> - Holistic: Measure from individual family, organization and structural level. - Adoption of "tree" as a metaphor for growth and empowerment. - Strength-based. 	<ul style="list-style-type: none"> - GME consists of two measures: <ol style="list-style-type: none"> 1. 14-item Emotional Empowerment Scale (EES-14): <ul style="list-style-type: none"> - Structure: 2 subscales/ factors: Inner Peace; Self-Capacity. - Reliability: Good 2. 12-item Empowerment Scenarios (12S): <ul style="list-style-type: none"> - Structure: 2 subscales/ factors: Healing; Connection. - ✓ Concurrent validity - Reliability: Good

8.	Hua Oranga (Fruits of Health) (Harwood et al., 2012; Kingi & Durie, 2000; McClintock et al., 2011)	Holistic Māori and Pacific People wellness (PROM)	New Zealand: Māori and Pacific People ; Administered to patients, health care providers and family/care givers	Determine improvements in physical, mental, spiritual, and family domains of health for Māoris with mental illness (McClintock, 2011) Validated for use with Māori and Pacific People with stroke (Harwood et al., 2012)	Māori Mental Health Framework. Holistic Māori model/perspective of wellbeing (Whare tapa wha ⁷), with four pillars: - Physical: Health is related to unseen and unspoken energies. - Mental: Mind and body are inseparable. - Physical: Good physical health is required for optimal development. - Family: Individuals are part of a larger social system.	- 20- item questionnaire - Structure: 2 subscales/ factors: Physical-mental; Spiritual-family (Harwood et al, 2012). - ✓ Sensitivity to change - ✓ Concurrent validity
9.	Indigenous Risk Impact Screen (IRIS) (Schlesinger et al., 2007)	Presence of alcohol, drug and mental health risks (PROM)	Australia: Aboriginal or Torres Strait Islander background; both patient and non-patient groups	Screening tool for determining the presence of alcohol and drug and mental health risks	Not reported.	- 13-item questionnaire - Structure: 2 sub scales/ factors: Alcohol/drugs; Mental health. - ✓ Content and face validity - ✓ Convergent validity - Reliability: Good
10.	Native Wellness Assessment (NWA) (Fiedeldej-Van Dijk et al., 2017)	Culturally-embedded wellness (PROM)	Canada: Indigenous peoples (First Nations, Métis, and Inuit) in treatment centers for addiction	To assess the effectiveness of culture-as-intervention, among those in alcohol and drug treatment programs	- Culture is protective and vital for healing. - Medicine Wheel - a holistic approach to wellness: Native wellness was defined as enablement of individuals and communities to actualize their potential emotionally, spiritually, mentally and physically. - Strength-based: Resiliency perspective on alcohol and drug addiction (not just focus on risks, disease and socioeconomic problems). Commonly held cultural beliefs (unifying concepts across culture): - Life on earth bonded to Spirit. - The circle: continuous flow of life. - Indigenous culture is voiced and transmitted from original language. - Universal things are connected. - Throughout life to live in harmony and balance.	- NWA includes: 66- cultural statements plus 39 cultural intervention practices (CIP) - NWA has two versions: Self-report form (S version) and a parallel observer form (O version). - Structure: 1 scale/factor– “wellness” - ✓ Convergent validity - ✓ Predictive validity - Reliability: Acceptable for S-version and good for the O-version
11.	Strong Souls (Thomas et al., 2010)	Social and emotional wellbeing in Indigenous youths (PROM)	Australia: Indigenous Youth (ages 16-20) from rural and urban Northern regions	Screening tool to assess wellness; potential to be used as health outcome measure	- Holistic: Health is defined in terms of the physical, emotional, cultural and spiritual wellbeing, not only for the individual but of the whole community. - Indigenous perspectives of mental health which include being in harmony with country, lawfulness, and social and kinship relationships.	- 25-item questionnaire - Structure: 4 subscales/ factors: Anxiety; Resilience; Depression; Suicide risk - ✓ Face validity - ✓ Construct validity - Reliability: Acceptable

12.	Transition Support Service Student Survey (T4S) (Mccalman et al., 2017)	Resilience and Risk for Self-Harm (PROM)	Australia: Aboriginal, Torres Strait Islander; Adolescents/ secondary students	Assess resilience and risk factors of secondary students; to assess outcomes after a resilience- based support program	<ul style="list-style-type: none"> - Strength-based, as opposed to deficit-based (focus on resiliency). - Cultural and holistic definition of resilience used. 	<ul style="list-style-type: none"> - 59-item questionnaire - Includes the following sections: Ability to cope with stress; Feeling supported; Family, community and culture engagement; Personal and social skills/leadership; Enhanced learning; Post-school aspiration; Safe environment and ability to deal with crisis; Access to and satisfaction with health services - ✓ Content validity & appropriateness
13.	Yup'ik Protective Factor Scale (Allen et al., 2006) <i>Later adapted for Youth:</i> Reflective Processes Scale (RPS) (Allen et al., 2012)	Protective factors of sobriety (Adult scale) Awareness of the consequences of alcohol use (Youth scale) (PROM)	United States: Alaska native - Yup'ik adults; later dapted for Yup'ik youth	Assessment of risk of alcohol use	<ul style="list-style-type: none"> - Ethical concerns over directly asking about alcohol use; importance of showing respect; instead asking about protective factors. - Heuristic model of protective factors of sobriety; with elements of individual, family, community, social characteristics, and trauma. - Awareness and thinking over negative consequences of alcohol use –taps the broader cultural value of awareness of interconnections between people, animal, and spirit worlds, and of the resulting consequences of one's actions. 	<p>Yup'ik Protective Factor Scale:</p> <ul style="list-style-type: none"> - 21--item-questionnaire - Structure: 4 subscales/ factors: Things I want for... (1) myself, (2) family, (3) body/wellbeing, (4) way of life. - ✓ Content validity - Reliability: Good to acceptable <p>Reflective Processes Scale (adapted for youth):</p> <ul style="list-style-type: none"> - 10-item questionnaire - Structure: 3 subscales/ factors: Things I want for.. (1) myself, (2) family, (3) way of life. - ✓ Convergent and discriminant validity
Patient-Reported Experience Measures (PREMs)						
14.	Cultural Safety Survey (Elvidge et al., 2019)	Cultural safety in hospitals (PREM)	Australia: Aboriginal and Torres Strait Islander in North South Wales	To measure cultural safety in hospitals from an Aboriginal patient perspective; Make health services accountable to the Aboriginal communities they serve	<ul style="list-style-type: none"> - Cultural safety: Centers around the subjective experiences of the recipient of care and health care providers' responsiveness to different cultural needs, and how their values can impact the care they provide. 	<ul style="list-style-type: none"> - 23-item questionnaire - Measuring five domains of cultural safety: (1) Positive communication between patients and hospital staff; (2) Negative communication between patients and hospital staff; (3) Trust between patients and hospital staff; (4) Hospital environment; (5) Support for Aboriginal families and culture. - Structure: 4 subscales/ factors- labels for factors not provided - ✓ Content validity - Reliability: Excellent to acceptable

15.	Equity Oriented Health Care Scale (EHoCS)* (Ford-Gilboe et al., 2018) (Worthington C et al., 2010) (Scale Development Briefing Notes, (July 6, 2020)	Equity oriented health care - whether care is equitable and tailored (PREM)	Canada: Marginalized groups (although not solely developed for Indigenous peoples, in their study 42% identified as Indigenous)*	Assess degree of equity oriented care in order to enhance capacity at the staff and organizational levels	- Equity-oriented primary health care. - Conceptual grounding: (1) Trauma-and violence informed care; (2) Culturally safe care; (3) Contextually-tailored care.	<u>12-item questionnaire (final version)</u> - ✓ Concurrent validity <u>24-item version:</u> - Structure: Uni-dimensional with 5 domains loading on a single factor; Domains: Promote accessibility and reduce barriers; Welcoming comfortable milieu; Emotional safety and trust; Non-discriminatory posture; Tailoring to context, history and experience. - ✓ Face validity - Reliability: Excellent for the overall scale and questionable to good for each domain
16.	HIV testing experiences of Aboriginal youth in Canada (Worthington C et al., 2010)	HIV testing experience (PREM)	Canada: Indigenous youth (15-30 yrs. of age) from 10 Canadian provinces and one territory (largely urban centers)	Assess HIV testing experiences among Indigenous Youth	- Principles of respect. - Cultural responsiveness: Importance of cultural practices in health care and the cultural competency of health care staff.	- 49-item questionnaire - Themes: Decision to test; Testing experience; Experiences of HIV care for those with HIV - ✓ Face and content validity
17.	Measure of Indigenous Racism Experiences (MIRE) (Paradies & Cunningham, 2008)	Self-reported racism (PREM)	Australia: Aboriginal, and/or Torres Strait Islander people	Assess self-reported racism	- Lived experiences of Indigenous residents.	- 31-item questionnaire - Consists of 6 multi-item scales: Assessing exposure to inter-personal racism; Response and reactions to racism; Internalized racism; Recognition of systemic racism; Race-consciousness; Salience of Indigeneity within social group and among strangers - Structure: Some scales were uni-dimensional and some had two subscales/factors - Content validity: Established via exploratory focus group. - ✓ Construct validity - ✓ Convergent validity - Reliability: Good to unacceptable
Population-Based PROMs & PREMs						
18.	Aboriginal Children's Survey (ACS) – 2006 (<i>Aboriginal Children's Survey,</i>	Wellbeing: Captured via wide range of topics (Population-based PROM)	Canada: Aboriginal children under 6 years of age (First Nations children living off reserve, Métis children and Inuit children) living in	To assess health, development and needs; to inform decision making and support academic research	- Holistic conceptualization of health.	- Questions cover: Child's health, sleep, nutrition, motor, social, and cognitive development, nurturing, child care, school, language, behavior, and activities, and demographical and socioeconomic data.

	2006, 2006; Oliver et al., 2009)		urban, rural and northern regions throughout Canada			<ul style="list-style-type: none"> - Includes the Strengths and Difficulties questionnaire (Goodman, 2001). - Information on psychometric testing is not available.
19.	Indigenous Peoples' Survey (IPS) (Turpel-Lafond, 2020)	Racism in the health care system (Population-based PREM)	Canada: Indigenous people in British Columbia	Capture experiences of racism and discrimination in the health care system to inform policy and practice changes	<ul style="list-style-type: none"> - Survey was developed as part of an independent review of Indigenous-specific racism in British Columbia's health care system. - No information is available regarding lens/framework. 	<ul style="list-style-type: none"> - 44-item questionnaire. - Questions centered around the following topics: Feeling of safety; Interaction with health care providers; Care outcomes; Perception of racism and equity; Making complaints; Perceived benefits of strategies to improve care experiences. - Information on psychometric testing not available.
20.	National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) - 2018 (Australian Bureau of Statistics, n.d.) Australian Bureau of Statistics (ABS)	Health status with focus on health conditions, lifestyle factors, health service use, social and emotional wellbeing, and physical measurements (Population-based PROM)	Australia: Aboriginal and Torres Strait Islander population	To better understand the health and wellbeing of Aboriginal and Torres Strait Islander peoples; to assist in improving services and health programs; to monitor health status across time and populations	<ul style="list-style-type: none"> - Social-determinant approach to health. 	<ul style="list-style-type: none"> - List of topics covered in the survey is available at: https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4715.0Appendix62.018%E2%80%9319 - Information on psychometric testing is not available.
21.	Regional Health Survey (RHS)- (with Adult, Youth and Child versions) (<i>First Nations Best Practice Booklet (FNIGC), 2011</i>) (<i>Review of the First Nations Regional Longitudinal Health Survey (RHS) 2002/2003, 2006</i>) (<i>National Reports of The First Nations Regional Health Survey PHASE 3: VOLUME 1, 2018</i>)	Health and wellness (Population-based PROM and PREM)	Canada: First Nations and Inuit adults, children (0-11) and youth (12-17) living on reserves	A national health survey conducted <i>by & for</i> First Nations, captures a snapshot of the health and wellness of First Nations peoples living on reserves across Canada	<ul style="list-style-type: none"> - Two-eye seeing: Embraced both western and traditional understanding of health. - RHS Cultural Framework: "Total health of the total person within the total environment"; represented by North: action (behaviors), South: Relationships (ways of relating to time), West: Reason (analysis), East: Vision (ways of seeing). - The concept of "total person" is defined to include all dimensions of personhood including body, mind, heart and spirit. - "Total environment" is defined as "a healthy connection and relationship with the living environment – this being constituted of the land, natural environment, cultural environment, context of activity, community, family, and the everyday living environment. 	<ul style="list-style-type: none"> - Core questions plus region specific questions; each year new themes/indicators are introduced. List of full indicators: https://fnigc.ca/sites/default/files/docs/fnigc_rhs_phase_3_national_report_vol_1_rev_july_2018.pdf. - ✓ Appropriateness and face validity - RHS has gone through an independent review by Harvard University in 2006 - Information on further psychometric testing is not available.

Adapted Tools (Mainstream Tools Modified and Validated for Use With Indigenous Peoples)

#	Instrument	Construct Measured	Population	Application	Indigenous Lens/ Knowledge or Cultural/ Theoretical Frameworks Used in Content Development	Description & Reliability/ Validity
22.	<p>Adapted Patient Health Questionnaire – 9 (aPHQ-9)</p> <p>(Brown et al., 2013; Hackett et al., 2016; The Getting it Right Collaborative Group et al., 2019)</p> <p>Original tool: PHQ-9 (Kroenke et al., 2001).</p>	<p>Depression</p> <p>Adapted the (PROM)</p>	<p>Australia: Aboriginal and Torres Strait Island men (Brown et al., 2013)</p> <p>Aboriginal and Torres Strait Island people (men and women) (Hackett et al., 2019)</p>	<p>Application: Screening tool for depression and assessing symptom severity; outcome assessment</p>	<ul style="list-style-type: none"> - Cultural-specificity: Different cultural groups experience and express psychological distress differently. 	<ul style="list-style-type: none"> - 9- item questionnaire - ✓ Face validity and acceptability - ✓ Criterion validity: - Reliability: Good
23.	<p>Alaska Native Cultural Identification (ANCI)</p> <p>(Allen et al., 2012; Fok et al., 2012)</p>	<p>Cultural identification; bicultural identification</p> <p>(PROM)</p>	<p>United States: Rural Alaska Yup'ik Native youth</p>	<p>To assess culture as protective factor in health promoting behaviour</p>	<ul style="list-style-type: none"> - Culture as protective factor. - Orthogonal Cultural Identification Theory: Identification with one culture is separate from one's identification with another culture. 	<ul style="list-style-type: none"> - 8-item questionnaire - Structure: 2 subscales/ factors: Alaska Native cultural identification; White American cultural identification - Reliability: Acceptable, but questionable for the White American cultural identification subscale
24.	<p>Asthma-Specific Quality of Life Questionnaire for Native American Adults (AQLQ-NAA)</p> <p>(Gupchup et al., 2001)</p>	<p>Asthma-specific quality of life</p> <p>(PROM)</p>	<p>United States: Native American adults in Albuquerque, New Mexico</p>	<p>Measure patient outcomes in clinical settings</p>	<ul style="list-style-type: none"> - Compared to the AQLQ-M, the AQLQ-NAA has more emphasis on social, community, and cultural activities. 	<ul style="list-style-type: none"> - 19- item questionnaire. - Structure: -3 subscales/ factors: Community and social restrictions; Psychological impact; Symptoms - ✓ Convergent validity - Reliability: Excellent to good
25.	<p>Multicultural Mastery Scale(MMS) for Youth</p> <p>(Fok et al., 2012)</p>	<p>Mastery: Problem-focused coping styles</p> <p>(PROM)</p>	<p>United States: 12 to 18-year-old predominately Yup'ik Eskimo Alaska Native adolescents</p>	<p>To assess youth coping, resiliency and health outcomes</p>	<ul style="list-style-type: none"> - Collectivism, in contrast to mainstream western individualistic orientations. - Belief that one can overcome stress by tapping the social/family/friends resources. 	<ul style="list-style-type: none"> - 13-item questionnaire (final version) - Structure: 3 sub-scales/ factors: Mastery-Friends; Mastery- Family; Mastery-Self - ✓ Convergent validity - ✓ Discriminant validity

					- Interconnectedness and expanded sense of self. Resilience focused.	
26.	<p>Orthogonal Cultural Identification Scale (OCIS) (Venner et al., 2006) (Validated for adults)</p> <p>Bicultural Ethnic Identity Scale (Moran et al., 1999) (Adapted for youth)</p>	<p>Strength of one's identification with each cultural way of life—American Indian identity and White identity</p> <p>(PROM)</p>	<p>United States: American Mission Indian adults (Venner et al., 2006); and American Indian youth between ages 14 to 19 years representing cultural groups from the South-Central, Northern Plains, and two distinct areas of the Southwestern United States (Moran et al., 1999)</p>	<p>To assess impact of cultural interventions that promote psychological wellbeing</p>	<p>- The Orthogonal Cultural Identification: Identification with one culture is separate from one's identification with another culture.</p> <p>- Culture as protective factor; strong identification with one or more Indian cultural groups serve as protective factors for a host of undesirable outcomes, such as addiction.</p>	<p>Adult scale (Venner et al., 2006):</p> <ul style="list-style-type: none"> - 12-item questionnaire - Structure: 2 subscales/ factors: Native American identification; Anglo identification - ✓ Concurrent validity - ✓ Discriminant validity - Reliability: Excellent to good <p>Youth Scale (Moran et al., 1999):</p> <ul style="list-style-type: none"> - 16-item questionnaire - Structure: 2 subscales/ factors: Native American identification; Anglo identification. - ✓ Construct validity
27.	<p>Reasons for Life (RFL)</p> <p><i>Alternative Name: Yuuyaraqegtaa = A Way to Live a Very Good, Beautiful Life</i></p> <p>(Allen et al., 2019)</p>	<p>Culturally-based Protective factors from suicide risk; beliefs and experiences that contribute to making life enjoyable, worthwhile, and meaningful for youth as protective factors for suicide.</p> <p>(PROM)</p>	<p>United States: Rural Alaska, Yup'ik Native Adolescents</p>	<p>To assess outcomes from strengths-based, culturally grounded suicide prevention efforts – to address concerns regarding direct assessment of suicide risk (as direct assessment can be viewed as stigmatizing, triggering and traumatizing in at risk communities)</p>	<p>- Indigenous wellbeing frameworks.</p> <p>- Strength-based; focus on strengths and positive attributes, hope and meaning in life, rather than risks.</p> <p>- Culturally-based protective factors.</p> <p>- Trauma-informed.</p>	<ul style="list-style-type: none"> - 11-item questionnaire (latest version) - Structure: 3 subscales/factors: Efficacy over life problems; Cultural and spiritual beliefs; Others assessment of me - ✓ Content and face validity - ✓ Convergent validity
28.	<p>Strengths and Difficulties Questionnaire (SDQ)</p> <p>(De Maio et al., 2005; Zubrick et al., 2005) (Adapted in Australia as part of the Western Australian Aboriginal Child Health Survey (WAACHS))</p>	<p>Mental health - strengths and difficulties over the last 6 months</p> <p>(PROM)</p>	<p>Australia: Aboriginal children between 4-17-years of age in urban New South Wales (Williamson et al., 2014) and Western Australia (WAACHS)- Youth</p>	<p>To assess psychological adjustments of children and youth; screening tool in medical practice and research; to assess treatment outcomes</p>	<p>Not reported.</p>	<ul style="list-style-type: none"> - 25-item questionnaire; focusing on strengths (10 items) and difficulties (15 items) - Structure: 5 subscales/ factors: Emotional symptom; Conduct problems; Hyperactivity; Peer problems; Pro-social skills – variability seen for the Peer-problems subscale - ✓ Acceptability - ✓ Convergent validity - Reliability: Good, with the exception of Peer problems subscale; reliability declines as the child resides in more remote locality

29.	Supportive Care Need Assessment Tool-Indigenous Population (SCNAT-IP) (Garvey et al., 2012, 2015)	Supportive care needs of Indigenous people with cancer as well as their experience with cancer care (PROM + PREM)	Australia: Aboriginal and Torres Strait Islanders with cancer	To assess support needs during cancer care; to understand gaps in care in order to better meet the needs of Indigenous cancer patients; to assess the impact of interventions	<ul style="list-style-type: none"> - “Living in now” perspective as opposed to focus on “uncertainty about future” . - Not focus on “control” when things are out of one’s hand (e.g., cancer). - Elimination of “culturally-loaded terms”, such as ‘cancer” and “death”. - Holistic definition of wellbeing– e.g., “pain” needs to be described (physical pain vs. emotional). - Importance of culture and family/community support in wellbeing. 	<ul style="list-style-type: none"> - 26- item questionnaire - Structure: 4 sub-scales/ factors: Physical and psychological; Hospital care; Information and communication; Practical and cultural needs - ✓ Face, content validity and cultural acceptability - ✓ Convergent validity. - Reliability: Good to acceptable
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Glossary of Terms

Adapted tools: Mainstream tools (PROMs or PREMs) developed for general or clinical population modified and validated for use with Indigenous peoples.

Concurrent Validity: The amount of agreement between a new measure and an old established measure of the same or related construct.

Construct validity: Extent to which the survey measures the theoretical construct it is intended to measure. In some cases confirmatory factor analysis (CFA) is used to assess construct validity.

Content validity: A survey has content validity if, in the view of experts and stakeholders, the survey contains questions which cover all aspects of the construct being measured. Face and content validity are subjective opinions of experts and stakeholders.

Convergent validity: The degree to which two measures of constructs that theoretically should be related are in fact related - refers to the observation of strong correlations between two tests that are assumed to measure the same construct. Convergent validity, along with discriminant validity, are subtypes of construct validity.

Criterion validity: There are two types of criterion validity: Concurrent and predictive – see Concurrent and Predictive validity in this glossary.

Developed tools: Measurement tools (PROMs or PREMs) developed specifically for Indigenous community members.

Discriminant validity: Demonstrated by evidence that measures of constructs that theoretically should not be highly related to each other are in fact not found to be highly correlated to each other.

Face validity: Extent to which a measure/tool appears, “on its face”, to measure the construct of interest. See also content validity.

Patient Reported Outcome Measures (PROMs): Survey instruments (tools) used to assess a patient's self-reported health status at a particular point in time. PROMs can be completed either during an illness or while treating a health condition. PROMs can also be used to assess health at the population level. From a social determinant approach to health, any components that impact health and wellbeing can be considered a health indicator and can be measured by PROMs.

Patient Reported Experience Measures (PREMs): Survey instruments (tools) measuring patients' perceptions of their experience whilst receiving care. Patient satisfaction surveys are examples of PREMs.

Predictive validity: Extent to which a score on a scale or measure predicts scores on some criterion measure.

Reliability: Ability of a scale to give consistent results. A measure of reliability reflects the extent to which items within an instrument measure various aspects of the same characteristic or construct. It measures whether several items that propose to measure the same general construct produce similar scores. Internal consistency is usually measured with Cronbach's alpha, a statistic calculated from the pairwise correlations between items. Internal consistency ranges between negative infinity and one. Coefficient alpha will be negative whenever there is greater within-subject variability than between-subject variability.

A commonly accepted rule of thumb for describing internal consistency is as follows:

Cronbach's Coefficient Alpha Ranges of Acceptability

$\alpha \geq 0.9$	Excellent
$0.8 \leq \alpha < 0.9$	Good
$0.7 \leq \alpha < 0.8$	Acceptable
$0.6 \leq \alpha < 0.7$	Questionable
$0.5 \leq \alpha < 0.6$	Poor
$\alpha < 0.5$	Unacceptable

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