



BMJ Open What Matters to Aboriginal and Torres Strait Islander Youth (WM2Y): a study protocol to develop a national youth well-being measure

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ABSTRACT

Introduction Adolescents face challenges associated with unprecedented environmental, social and technological changes. The impacts of colonisation, intergenerational trauma, racism and socioeconomic disadvantage intensify these challenges for many Aboriginal and Torres Strait Islander adolescents. However, Aboriginal and Torres Strait Islander adolescents also have cultural, spiritual, family and community capital that fosters their well-being.

To date, little research has focused on understanding and appropriately measuring the well-being of Aboriginal and Torres Strait Islander adolescents, a pivotal factor in informing and guiding programmes and interventions that support them. This study will identify the domains of well-being and develop a new preference-based well-being measure based on the values and preferences of Aboriginal and Torres Strait Islander youth (aged 12–17 years).

Methods and analysis This project will be conducted across three research phases: (1) qualitative exploration of well-being using PhotoYarning and yarns with adult mentors to develop candidate items; (2) Think Aloud study, quantitative survey, psychometric analysis, validity testing of candidate items and finalisation of the descriptive system; and (3) scoring development using a quantitative preference-based approach. A multinomial (conditional) logit framework will be used to analyse responses and generate a scoring algorithm for the new preference-based well-being measure.

Ethics and dissemination Ethics approvals have been obtained from: the Human Research Ethics Committees for each state and territory where data are being collected, the institutions where the research is being conducted and from the relevant Departments of Education. The new well-being measure will have wide applicability and can be used in assessing the effectiveness of programmes and services. This new national measure will ensure benefit and positive impact through the ability to identify and measure the aspects of well-being important to and valued by Aboriginal and Torres Strait Islander youth. Results will be published in international peer-reviewed journals and presented at conferences, and summaries will be provided to the study partner organisations and other relevant organisations.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study will adopt a strengths-based Indigenist research approach, guided by the key principles of prioritising and privileging the voices and perspectives of Aboriginal and Torres Strait Islander youth.
- ⇒ PhotoYarning, an adaptation of Photovoice and Yarning methodologies, will be used to explore what matters in lives and is important to, and impacts on, the well-being of Aboriginal and Torres Strait Islander youth.
- ⇒ Think Aloud methods and online surveys will be used to assess the interpretation, understandability and psychometric properties of the measure's descriptive system.
- ⇒ Participants will be recruited primarily from two partner organisations that have sites across Australia and while this could be viewed as a strength, it is also a limitation of the study.

INTRODUCTION

In Australia, Aboriginal and Torres Strait Islander communities are resilient, and adolescents from these communities have cultural, spiritual, family and community capital that fosters well-being.¹ Importantly, these protective factors are likely to impact on the mental health and well-being of Aboriginal and Torres Strait Islander adolescents.² At the same time, Aboriginal and Torres Strait Islander adolescents experience a disproportionately high level of disadvantage compared with their non-Indigenous counterparts.³ This is particularly apparent in mental health indicators, with higher rates of psychological disorders, suicide and incarceration among Aboriginal and Torres Strait Islander adolescents than their non-Indigenous counterparts.¹ Mental health challenges in adolescence are associated with poorer social, educational and physical health outcomes that can persist throughout the lifespan in

the absence of timely, culturally appropriate support.² Despite the disparities facing Aboriginal and Torres Strait Islander adolescents, a dearth of culturally appropriate measures to assess well-being and mental health in this population has severely hindered the development of a robust evidence base of protective and risk factors, and of the efficacy of programmes and interventions aimed at improving the social and emotional well-being of Aboriginal and Torres Strait Islander adolescents.^{1,4}

Adolescence is the transitional period between childhood and adulthood, and is typically defined as taking place between the ages of 10 and 24 years old.⁵ While all adolescents face challenges in an intense period of brain development and major life transitions alongside increasing associated unprecedented environmental, social and technological changes, the impacts of colonisation, intergenerational trauma, racism and socioeconomic disadvantage intensify the challenges faced by Aboriginal and Torres Strait Islander adolescents.⁵ The resilience of Aboriginal and Torres Strait Islander youth has been intricately tied to culture, kinship, family, historical roots, and the extent of familial conflict or family unity.⁶ To date, little research has focused on understanding the nature and impact of protective and risk factors on the well-being of Aboriginal and Torres Strait Islander adolescents, which is required to build an evidence base that prioritises their worldviews and cultural strengths, and informs the development and evaluation of initiatives designed to strengthen or improve social and emotional well-being.¹ This research and evidence gap can be realised through the development of a specific measure that can reliably and validly measure well-being for Aboriginal and Torres Strait Islander adolescents.

Within the linguistic and cultural diversity of Aboriginal and Torres Strait Islander peoples and communities, common understanding of mental health and well-being (often called *social and emotional well-being*) is widely acknowledged as being holistic, multidimensional and connected with community, culture and country.⁷ This holistic understanding of well-being is not captured in prevailing biomedically based mental health and quality of life measures, which typically focus on illnesses and pathologies,^{8,9} nor are these existing measures informed by the values and preferences of Aboriginal and Torres Strait Islander adolescents. While the absence or presence of mental pathology undeniably impacts on well-being of Aboriginal and Torres Strait Islander adolescents, measurement of this alone does not provide insight into experiences of holistic well-being. The ability to appropriately measure well-being is a pivotal factor in informing, guiding and evaluating successful mental health programmes and interventions, and in identifying protective and risk factors for mental health and well-being.⁴

To date, only a handful of mental health measures have been developed specifically for Aboriginal and Torres Strait Islander children and adolescents,^{10–13} with validation undertaken in discrete geographical or clinical populations.^{14,15} While valuable in specific clinical

settings, they do not offer a nationally and culturally relevant measure of well-being for Aboriginal and Torres Strait Islander adolescents to evaluate mental health and well-being policies and programmes. Critically, for policy decision-making, they also do not allow estimation of quality-adjusted life years (QALYs), an outcome used in economic evaluation and familiar to policymakers. While there has been a recent focus on the development of well-being measures for adults, including our own What Matters 2 Adults (WM2A) Study,^{16–18} this is not the case for Aboriginal and Torres Strait Islander adolescents.

Study aims

The What Matters 2 Youth (WM2Y) Project aims to develop a new nationally relevant, strengths-based well-being measure for Aboriginal and Torres Strait Islander youth that is grounded in their experiences, values, preferences, aspirations and culture, to inform clinical and policy decision-making. The focus will be on Aboriginal and Torres Strait Islander youth aged 12–17 years old, as they have different experiences and needs from younger and older adolescent groups.¹¹ Specifically, we will:

1. Identify the dimensions of well-being that are important to Aboriginal and Torres Strait Islander youth (phase 1).
2. Develop and validate a descriptive system for this new measure that appropriately captures these aspects (phase 2).
3. Develop a scoring system for this measure that is based on the values and preferences of Aboriginal and Torres Strait Islander youth (phase 3).

Approach to research

The WM2Y Project will adopt a strengths-based Indigenist research approach,^{19,20} guided by the key principles of prioritising and privileging the voices, perspectives and preferences of Aboriginal and Torres Strait Islander youth in research processes and the resulting measure. An Indigenous Project Advisory Group (IPAG) will be established consisting of Aboriginal and Torres Strait Islander young people who work with Aboriginal and Torres Strait Islander youth to provide guidance throughout all aspects of the project. Additionally, throughout the study, our team has built in multiple opportunities and mechanisms for youth to review, provide feedback and guide findings. Our experienced, Aboriginal-led team are well positioned to enact these methods and ensure the project processes and outputs align with Aboriginal and Torres Strait Islander values. In addition, we have partnered with two key organisations (the Moriarty²¹ and STARS Foundations²²) that have established relationships with schools and communities across multiple Australian jurisdictions to support Aboriginal and Torres Strait Islander youth through sporting and mentorship programmes. These partner organisations will guide the project planning in terms of participant recruitment, data collection, dissemination and implementation of the study outputs.

The study will be conducted in accordance with the values and ethics of Aboriginal people, as described in the National Health and Medical Research Council guidelines for ethical conduct in research with Aboriginal and Torres Strait Islander peoples.^{23 24} The CONSolidated critERia for strengthening reporting of health research involving Indigenous Peoples statement²⁵ will be used to strengthen the research approach and project reporting.

METHODS

The aims of this project will be addressed across three phases. Guided by the principles and considerations for ground-up measure development,^{26–29} our research phases include a qualitative exploration using PhotoYarning³⁰ and quantitative psychometric and preference-based methods, such as Best–Worst Scaling (BWS) surveys.

Phase 1: qualitative exploration of well-being (aim 1)

Research design

This phase will address aim 1 and involves a large qualitative study using a PhotoYarning³⁰ methodology to privilege the voices of Aboriginal and Torres Strait Islander youth about what matters in their lives and is important to, and impacts on, their well-being. PhotoYarning is an adaptation of Photovoice³¹ and Yarning methodologies.³²

Photovoice engages participants as co-researchers and provides opportunities for them to contribute to data analysis and theme generation. Photovoice is an established method that uses photographs taken and selected by participants, to respond to and reflect upon a theme/topic and explore the reasons, emotions and experiences that have guided their chosen images.³¹ This method offers Aboriginal and Torres Strait Islander youth the opportunity to engage in research in a way that is accessible and constructive, as well as offering potential to strengthen their identity and agency as changemakers in their communities and society.³³ This method's flexible nature means that it can easily be adapted to suit a range of participants (eg, different age ranges, and variable literacy and comprehension levels) and community contexts (eg, remote communities and discrete groups). Photovoice adaptations have been used in Australia with Aboriginal and Torres Strait Islander communities to qualitatively explore diverse issues such as food security, health and health workers, transitioning to school and environmental concerns.^{30 34–36} In Australia and internationally,^{37–41} Photovoice has been used effectively with Indigenous youth populations, due to the ability of photography to engage youth and build relational connections between participants and researchers to foster in-depth discussions.

Yarning methodology prioritises Indigenous ways of communicating and sharing knowledge in a culturally supported and respectful space. This method of gathering information respects Aboriginal and Torres Strait Islander peoples' oral traditions and values, and privileges Indigenous knowledge.³²

Combined, Photovoice and Yarning, referred to as *PhotoYarning*, provides an ideal and culturally appropriate methodology to engage Aboriginal and Torres Strait Islander youth in knowledge-sharing about aspects of their lives that affect and are important to them and their well-being. PhotoYarning also addresses the power imbalance that often occurs in research and empowers the participants, in this case, Aboriginal and Torres Strait Islander youth as the knowledge holders.

Participants and data collection

Approximately 200 Aboriginal and Torres Strait Islander youth aged 12–17 years old will be recruited from communities across Australia by Indigenous partner support officers (PSOs). This sample size is well above what is required for qualitative studies where the study size ranges from 5 to 20. Our sample size will allow more than adequate data saturation from the perspectives of Aboriginal and Torres Strait Islander youth across remote, regional and urban centres. PSOs will be funded by the project and located within our partner organisations (the Moriarty²¹ and STARS Foundations)²² to facilitate recruiting participants, gaining parental consent and organising venues and light refreshments for participants. Indigenous research officers (IROs) will be trained and mentored by senior members of the research team to facilitate the PhotoYarning sessions. Data collection with Aboriginal and Torres Strait Islander youth includes an Information Session, a PhotoYarning session and Yarning Circles in a smaller number of sites to confirm the preliminary themes and seek feedback on draft well-being candidate items. Each of these sessions will be held with 8–10 youth.

Adult mentors (n=20) who work with Aboriginal and Torres Strait Islander youth will be recruited from the same sites to participate in an online individual yarn with one of our IROs. The yarns will explore the perspectives of adult mentors on what parts of life are important in supporting the well-being of the Aboriginal and Torres Strait Islander youth. Data collection with adult mentors comprises one online individual yarn.

Patient and public involvement

None.

The Information Session will provide participants with an overview of the study aims, purpose of the research and information about PhotoYarning methods. Each participant will be given a digital camera and instructions on how to operate it and asked to take photos of things in their lives that contribute to their well-being. They will be instructed on the things to remember when taking photos such as not worrying about the quality of the photo but rather focus on the content and what makes a good life for them, and not to take photos of embarrassing, distressing or culturally inappropriate situations.

The PhotoYarning session will be audio-recorded, and each participant will be asked to share around 5–10 photos with the group. These will be uploaded into a PowerPoint presentation to share with the entire group. The IRO will

facilitate a yarn about the photos and ask each participant to share with the group some information about the photo(s) they took and why it was important to them and to their well-being. The IRO will facilitate a general yarn with all participants about the photo and if the content was also important to them and their well-being.

While the yarns will be largely responsive to the topics generated by the participants and their photos, we will also refer to our previous well-being research conducted with Aboriginal and Torres Strait Islander adults^{16 17} to explore components of well-being that may also be important to Aboriginal and Torres Strait Islander youth but were not captured in the submitted photos.

Yarning with adult mentors will be held one on one with the IRO and will be audio-recorded. The IRO will use a yarning guide to structure the yarn, which will complement the yarns with youth.

Well-being themes and statement checking yarns will be held in a subset (n=4 groups) of the sites visited in phase 1. Sites in diverse geographical locations will be invited to participate in these yarns and the final four sites will be determined based on their level of interest and availability. Yarning Circles will be held at each of these four sites to confirm the preliminary themes and to explore any connections between the different aspects of well-being, ensure no themes were missing and seek feedback on the wording of the draft statements. Each of these circles will be held with 8–10 youth.

Data analysis

In line with an Indigenist research approach, the worldviews and voices of Aboriginal and Torres Strait Islander people will be privileged in all aspects of the analysis.²⁵ A number of collaborative and iterative steps will be included in our analysis process, all of which will be led by Aboriginal and Torres Strait Islander researchers.⁴²

The audio-recordings from the yarns (youth and adult mentors) will be transcribed verbatim and imported into NVivo V.12 software⁴³ for analysis. A reflexive thematic analysis⁴⁴ will be used, whereby transcripts will be reviewed line by line to inductively generate a draft thematic framework relating to the parts of life identified as important to the well-being of participants. Our team recognises and acknowledges the individuality and diversity among Aboriginal and Torres Strait Islander youth⁴⁵; and our analysis process will aim to identify those parts of life that, if not identified universally by participants, are identified as important across a significant majority of participant groups. Within the larger research team, Aboriginal and Torres Strait Islander researchers will iteratively review and revise the draft thematic framework via reflection on extracted raw data to develop a final coding approach. Members of the research team will recode the transcripts in line with the revised thematic approach and prepare summaries of the themes.

Following thematic analysis, we will draft a number of culturally meaningful strengths-based well-being statements generated from the data. The thematic analysis

and draft well-being statements will be refined in an iterative manner with input from the IPAG to ensure the findings capture the full breadth and depth of data and the cultural context. The IPAG will also provide input on the draft response scales for these statements (eg, frequency (never, often, always) or severity (none, a little, a lot)-based scales).

Phase 2: psychometric testing and descriptive system development (aim 2)

Research design

This phase will evaluate the well-being statements from phase 1 using Think Aloud methods and an online survey to assess the interpretation and understandability, as well as psychometric properties of the newly developed descriptive system. Think Aloud is a method where the participant verbalises their thoughts while performing a task. This method has been effectively applied to health research, and research focused on designing and developing measures and tools.^{27 46} This method has been successfully used with Aboriginal and Torres Strait Islander adults in developing our WM2A well-being measure.^{18 47}

Recruitment and data collection

Think Aloud study

A Think Aloud study will be conducted and audio-recorded with Aboriginal and Torres Strait Islander youth (n=15). We will assess the well-being statements generated from phase 1 for face validity (eg, were the statements difficult to understand) and content validity (eg, are statements missing that should be included to accurately capture the key elements of youth well-being). Participants will be recruited via the PSOs to maximise diversity (eg, age, sex and remoteness).

Online survey

An online survey with at least 200 Aboriginal and Torres Strait Islander youth (12–17 years) will be conducted where participants will complete all well-being statements using the response scales and items finalised after the Think Aloud study. Participants will be recruited through our partner organisations and PSOs, and through email and social media flyers distributed via investigator and research team networks.

Data analysis

Think Aloud study

Thematic analysis will be conducted of the transcripts from the Think Aloud study. The wording of statements will be modified based on participant feedback.

Online survey

Psychometric analysis will be used at the item and dimension level to assess reliability and validity, for example, extent of missing data (<5%); item redundancy (inter-item correlation <0.75); endorsement frequencies and floor/ceiling effects (<80%). Differences across socio-demographic groups will also be explored. To ensure

the final measure includes a broad set of dimensions of well-being relevant to youth, we will conduct Exploratory Factor Analysis to examine dimensionality of groups of well-being statements, without imposing a prespecified structure of dimensions. Statements that do not load on any factor will be considered for exclusion from the measure alongside other criteria to ensure that crucial statements (eg, identified as important in phase 1) are not excluded. Confirmatory Factor Analysis will be used to test the preferred dimension structure, and other statistical analyses will assess the model fit and guide dimension development. Item Response Theory methods^{48 49} will be used to understand measurement characteristics of the statements and to inform decision-making about the final statements to include in the measure. These analyses and outcomes will be presented to, discussed and finalised with the IPAG.

Phase 3: scoring system development (aim 3)

Research design

A preference-based scoring system will be developed for the WM2Y well-being measure, by estimating the relative weight assigned to each attribute and level defined by the descriptive system developed in phase 2. Best practice methods for the design and analysis of BWS surveys⁵⁰ will be used following an approach used for the preference-based scoring for the WM2A well-being measure.¹⁸ This approach allows development of a preference-based scoring algorithm to estimate overall and dimension-specific well-being scores from the WM2Y measure. It can also be built upon to potentially allow quantitative estimation of relative health and well-being (analogous to but broader than QALYs). QALYs provide a relatively narrow conceptualisation of quality of life and health. WM2Y captures holistic understanding of well-being for Aboriginal and Torres Strait Islander youth; therefore, it will be broader than existing multi-attribute utility instruments. From this phase, the final tool will generate a preference-weighted scoring system.

Data collection

The BWS survey will be pilot tested with a small number of youth (n=10) prior to the main survey to ensure that the BWS tasks are able to be understood and completed. The survey will consist of 10 BWS tasks, each of which presents a list of three different descriptions or statements of well-being based on the measure and response scales finalised in phase 2. The survey will also include sociodemographic questions. For each BWS task, participants will be asked to choose the best and the worst aspects of well-being in each task. We have successfully used this method previously with children and adolescents.^{8 51 52}

We will recruit a minimum of 1000 adolescents, aged 12–17 years, who are participating, or who have previously participated, in partner organisation programmes and other groups and organisations (eg, youth, community and sporting groups) to take part in this evaluation survey. Participants will be invited via email or face-to-face

invitations distributed via PSOs and through investigator networks via the IROs. A broad range of youth will be included to enable us to examine any differences across sociodemographic (eg, age group, sex) and geographical groups (eg, remoteness).

The optimal sample size for a BWS survey is dependent on the final number of items and levels in the well-being measure descriptive system,⁵³ as determined by phase 2. It is not feasible to present all combinations of well-being statements to participants. We will use a partially balanced incomplete block design⁵⁴ to maximise the occurrence of each statement and combinations of statements. For example, a partially balanced design of 150 unique BWS tasks (each with different combinations of well-being statements) could be blocked into 15 blocks of 10 tasks. Participants would then be randomised to complete 1 of the 15 blocks. The analysis of best and worst choices across all blocks allows the relative importance of all well-being statements to be determined. Given large sample properties can be achieved with 50 respondents per block,^{50 52} a design with 15 blocks and at least 65 respondents per block (n>975) will be sufficient to estimate main effects and first-order interactions and examine differences between participant subgroups. This sample size is also consistent with previous successful applications of this method,^{8 52 55} and with our own work developing the WM2A well-being measure for adults.¹⁸

Data analysis

Paired and marginal models for the prediction of well-being values will be estimated using data from the BWS tasks. The BWS will first be analysed using conditional logistic regression models. These will be used to estimate paired (maxdiff) models where the best–worst pair is the unit of analysis, and sequential best–worst models where the item level is the unit of analysis.^{8 50 52} Preference heterogeneity will be investigated via covariate-adjusted regression, random parameter versions of these models and latent class analysis. The estimates from the BWS task are initially anchored to the least valued dimension level. Since these estimates are on an interval scale, a linear transformation can be applied to the dimension-level estimates to ensure that the highest well-being state (ie, the sum of the best level values of all dimensions) takes the value 100 and the lowest well-being state (ie, the sum of the worst levels) takes the value 0. A similar process can be applied to each separate dimension, such that a dimension-specific score on a suitable scale, for example, 0–1, can also be estimated. The resulting regression models will be evaluated for monotonicity (ie, that the response levels within an item follow the expected direction from best well-being to worse well-being) with the final scoring algorithm based on a monotonic regression model. With an additional anchoring step, the preference-based values could also be used to calculate an outcome akin to, but broader than, QALYs, if deemed appropriate by the research team and IPAG.

ETHICS AND DISSEMINATION

Ethics approvals have been obtained from the Aboriginal Health and Medical Research Council of New South Wales (ref: 1717/20); Central Australian Human Research Ethics Committee (ref: CA-20-3915); Menzies School of Health Research and Northern Territory Department of Health Human Research Ethics Committee (ref: 2020-3850); Edith Cowan University Human Research and Ethics Committee (ref: 2020-02083); University of Sydney Human Research Ethics Committee (ref: 2021/011); Western Australian Aboriginal Health Ethics Committee (ref: HREC1027); the University of Queensland (ref: 2021/HE002563); the Northern Territory Department of Education (ref: 17565); the New South Wales Department of Education (ref: 21/91320); the Western Australia Department of Education (ref: D22/0106995); and the Aboriginal Health Council of South Australia (ref: 04-20-908). Prior to submission of any publications, approval will be sought from the Aboriginal Health and Medical Research Council of New South Wales (ref: 1717/20). Results will be published in international peer-reviewed journals and presented at conferences, and summaries will be provided to the study partner organisations and other relevant organisations. Youth participants will receive study communications via their partner organisations.

DISCUSSION AND CONCLUSION

There is a need for a culturally appropriate measure of well-being for Aboriginal and Torres Strait Islander youth.^{1 4 5} The guiding principle to developing this new measure is to ensure benefit and positive impact for Aboriginal and Torres Strait Islander people, in all aspects of the research. Benefit will be derived from the novel ability to measure the well-being of Aboriginal and Torres Strait Islander youth via assessing culturally relevant and evidence-based aspects of life that matter to this population. This new measure will have wide applicability and facilitate robust and culturally relevant decision-making and evaluation (including economic evaluation) of mental health and well-being policies and interventions for Aboriginal and Torres Strait Islander youth.

We will use a rigorous mixed-methods approach that draws on Indigenous research methodologies and approaches^{19 32} and considers the research design and the implications for youth and their communities.⁵⁶ A strengths-based Indigenist research approach^{19 56} will be guided by the key principles of prioritising and privileging the voices, views and perspectives of Aboriginal and Torres Strait Islander youth. The new WM2Y well-being measure will measure and value well-being dimensions important to Aboriginal and Torres Strait Islander youth with a preference-based scoring system that is underpinned by their values and preferences. Results will be disseminated through direct engagement with policymakers, key government agencies and Aboriginal and Torres Strait Islander communities, organisations

and participants, and through academic journals, professional conferences and policy forums.

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Competing interests None declared.

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