

Pre-testing a culturally adapted developmental outcome measure for Aboriginal and Torres Strait Islander children

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Abstract

Purpose Early childhood is of critical importance in building a foundation for children's lifelong development. Developmental outcome measures used within dominant Western cultures lack cultural appropriateness and validity in the Australian Aboriginal and Torres Strait Islander population. The Ages & Stages Questionnaire-STEPs for Measuring Aboriginal Child Development (ASQ-STEPs) is a culturally adapted developmental outcome measure that is being developed for Australian Aboriginal and Torres Strait Islander children aged one to four years. This paper aimed to describe the pre-testing process for the ASQ-STEPs prototype; the functionality of the ASQ-STEPs prototype in practice; and the acceptability of the culturally adapted Ages & Stages Questionnaires[®], Third Edition (ASQ-3)[®] items and accompanying illustrations for caregivers and practitioners in two Australian Aboriginal and Torres Strait Islander communities.

Methods The study was conducted in partnership with two Aboriginal community-controlled health services. Participants included practitioners who would administer the ASQ-STEPs, caregivers and their children

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aged 1 to 48 months. Study measures included the ASQ-STEPS pre-testing prototype, observation record, post-administration meeting record and focus group/semi-structured interviews.

Main findings Three practitioners and 18 caregivers participated. Of the 18 caregivers, 15 provided feedback through focus groups or interviews. The findings showed that the ASQ-STEPS was acceptable to caregivers and practitioners. They reported that the ASQ-STEPS items were clear and easy to understand. The caregivers and practitioners made several important recommendations for modifications to the culturally adapted ASQ-STEPS. This has led to an improved prototype ready for validation.

Principal conclusions This pre-testing study found that caregivers and practitioners made several important recommendations for modifications to the culturally adapted ASQ-STEPS. This step has led to an improved prototype that is ready for validation and highlights the value of engaging and consulting with partners in the pre-testing phase, to better understand the community needs and co-create the final tool. To date, there has been a scarcity of literature providing detailed accounts of the pre-testing process in the cultural adaptation of a child development screening tool or outcome measure. While some studies outside this area have provided a more detailed framework to follow, this study includes a detailed account of the pre-testing process in the Aboriginal and Torres Strait Islander context, incorporating strong Aboriginal and Torres Strait Islander governance, which can be used as an example for future research projects.

Keywords: Aboriginal and Torres Strait Islander; Early childhood; Outcome assessment; Cultural adaptation; Pre-testing

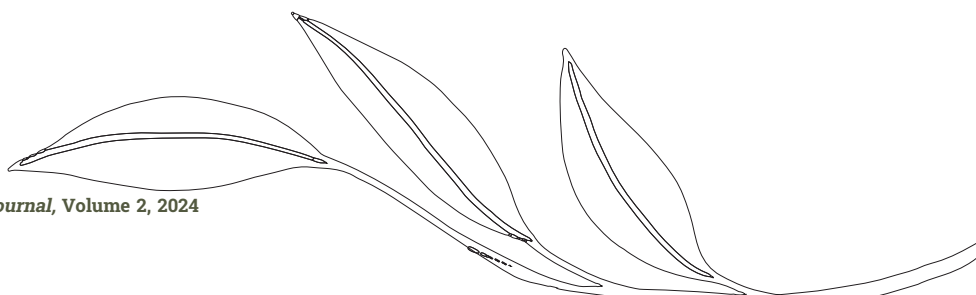
Highlights

- The study documents process for pre-testing a culturally adapted instrument.
- Participants found the ASQ-STEPS prototype to be functional and acceptable.
- Pre-testing highlights the value of community engagement and consultation.
- Pre-testing in target population checks appropriateness of adaptation.
- Pre-testing culturally adapted instruments is essential prior to validation.

Introduction

Early childhood is of critical importance in building a foundation for children's lifelong development (Australian Government Department of Education 2022; Shonkoff et al. 2000). During these early years, from conception to starting school, children experience rapid changes in all areas of their development (Berk 2012; Fernald et al. 2009). Early childhood is unique in that children are maximally

receptive to benefitting from early intervention, while also being most vulnerable to the impacts of developmental risk factors (Clifford et al. 2018; Fernald et al. 2009; Reynolds et al. 2001). Research shows that early childhood development programs can improve the developmental and social outcomes of vulnerable children (Engle et al. 2011; Heckman 2012; Holzinger and Biddle 2015). The later that problems are identified, the more difficult they are to resolve and



the more likely that they will escalate over time (Guevara et al. 2013). It is therefore crucial that developmental vulnerabilities are detected, and appropriate interventions and support are implemented as early as possible.

Aboriginal and Torres Strait Islander peoples have deep and long connections to Country, culture, language and community, and they share a continuing legacy of resilience, strength and determination. However, colonisation has had devastating and long-lasting impacts on Aboriginal and Torres Strait Islander peoples: dispossession, racism, systemic abuse and stolen wealth continue to affect their health and wellbeing (Dudgeon et al. 2023; Department of Health 2016; Truong and Moore 2023). Furthermore, successive policy failures have resulted in Aboriginal and Torres Strait Islander children experiencing disproportionate disadvantage in developmental outcomes. The most recent Australian Early Development Census (AEDC 2022) data report significant increases in the developmental vulnerability of Aboriginal and Torres Strait Islander children since 2018. According to the AEDC, 34% of Aboriginal and Torres Strait Islander children are developmentally on track compared with 56.2% of children overall. This is an instrument typically completed by teachers early in the first term of the first year of school.

Developmental outcome measures

Experts recommend measuring child development outcomes as part of program implementation (Aboud et al. 2018). Developmental outcome measures are one way of evaluating the effectiveness and impact of early childhood development programs, as well as determining the factors that contribute to improved outcomes (Goldfeld and Yousafzai 2018; Milner et al. 2019). This is one way to ensure that limited funding and resources are effectively used. A developmental

outcome measure provides a comprehensive assessment of a child's development across various domains, including motor, cognitive, language and social-emotional development. This contrasts with developmental screening tools, which provide a brief evaluation of a child's development and facilitate early identification of developmental difficulties. Screening tools have a limited number of items per age interval, do not provide detailed information about a child's ability and are not designed to monitor developmental progress over time; hence, their utility as a developmental outcome measure is limited (Bricker et al. 2010).

There are several desired features of developmental outcome measures used for program evaluation, they should: assess more than one developmental domain; have enough items to more accurately reflect a child's true ability; and be sensitive enough to detect changes over time and between children (Fernald et al. 2017). Instruments such as the Bayley Scales of Infant and Toddler Development and the Griffith Mental Development Scales have been used to measure child development outcomes in Australia (Bayley 2006; Luiz et al. 2006). While suitable within dominant Western cultures, the use of these tools, particularly in rural and remote Aboriginal and Torres Strait Islander settings, is limited by the level of administrator training required, implementation costs and the lack of cultural appropriateness and validity for the Australian Aboriginal and Torres Strait Islander population. This is a significant gap; cultural adaptation of existing measures is one way to address this disparity.

Cultural adaptation of instruments

The lack of culturally adapted developmental outcome measures for Australian Aboriginal and Torres Strait Islander children is a significant gap. Cultural adaptation is a process where an existing tool



is adapted to be culturally relevant and applicable for use in a different population than the one for which it was originally created (Beaton et al. 2000). Tools that are used outside of the population for which they were developed may not be valid (Cook et al. 2015) and culturally inappropriate tools are at risk of under- or over-recognising developmental difficulties. Cultural adaptation is the preferred process over developing new tools because it is often considered the more feasible and cost-effective approach. Although adaptation may follow multiple approaches, it typically includes consideration of cultural, linguistic, accessibility and administration elements of the pre-existing instrument. It should then be reviewed by a committee of relevant experts at the end of the modification process before being pre-tested and moving onto the validation stage (International Test Commission 2017; Rousseau et al. 2021).

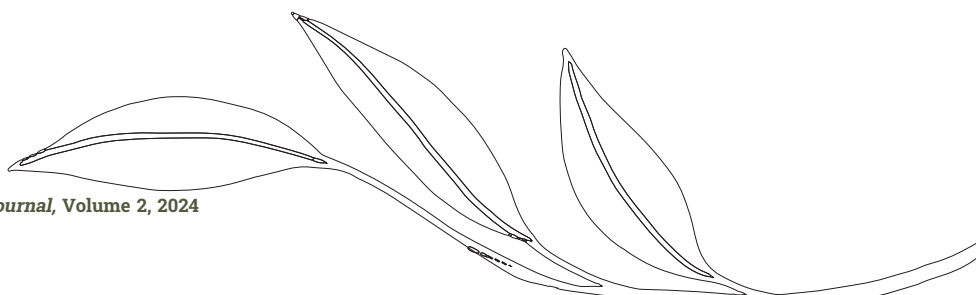
Developing the ASQ-STEPS for Measuring Aboriginal Child Development - Cultural adaptation of the ASQ: Extended

The ASQ-STEPS for Measuring Aboriginal Child Development (ASQ-STEPS) is a culturally adapted developmental outcome measure that is being developed for Australian Aboriginal and Torres Strait Islander children aged 1 to 4 years. This tool is a derivative of the ASQ-Talking about Raising Aboriginal Kids (ASQ-TRAK) developmental screening tool, which is a strengths-based, culturally responsive tool, co-created with two Aboriginal communities. In the ASQ-TRAK study, 7 of 21 Ages & Stages Questionnaires, Third Edition (ASQ-3)[®] were culturally adapted for Aboriginal children living in remote Australia (D'Aprano et al. 2016). This included modification of the questions to be more culturally appropriate, use plain language and culturally relevant images, and, in contrast to the ASQ-3[®], only be administered by interview with the caregiver and child. Evidence and practice confirm that the ASQ-TRAK is highly accepted by services and

families (D'Aprano et al. 2020; Johansen et al. 2020) and is now being used by health, education and community service sectors across Australia in urban, rural and remote settings (D'Aprano et al. 2022). However, in view of its cultural relevance, the ASQ-TRAK is being 'stretched' beyond the use for which it was designed (Bricker et al. 2010) and is being used as an outcome measure in some settings. Like other screening tools, the ASQ-TRAK is limited in its ability to measure developmental growth over time; the ASQ-STEPS is being developed for this purpose.

The ASQ-STEPS has been developed using a template of the ASQ: Extended, a derivative of the ASQ-3[®] (Clifford et al. 2018). The ASQ: Extended is a single measure of child development created by the ASQ-3[®] authors for the USA population. The ASQ: Extended includes ASQ-3[®] items from all 21 age intervals, allowing for more comprehensive assessment of a child's development in each developmental area or 'domain' (Communication, Gross Motor, Fine Motor, Problem Solving and Personal-Social). The ASQ: Extended combines all ASQ-3[®] items into a single scale, grouped by developmental domain, and hierarchically ordered according to difficulty (Figure 1). The expanded scale of the ASQ: Extended, with approximately 60 items per domain, in contrast to the six targeted items for each domain in the ASQ-3[®] and the ASQ-TRAK, supports repeated administration to ascertain the upper and lower ranges of a child's developmental capability through administration of a selection of the items based on the child's chronological age. Basal and ceiling rules (start and stop points) determine which items are administered. A child's development can be tracked on a percentile chart to show change or developmental growth over time.

Given the existing cultural modifications to ASQ-3[®] items to create the ASQ-TRAK, and the acceptability to



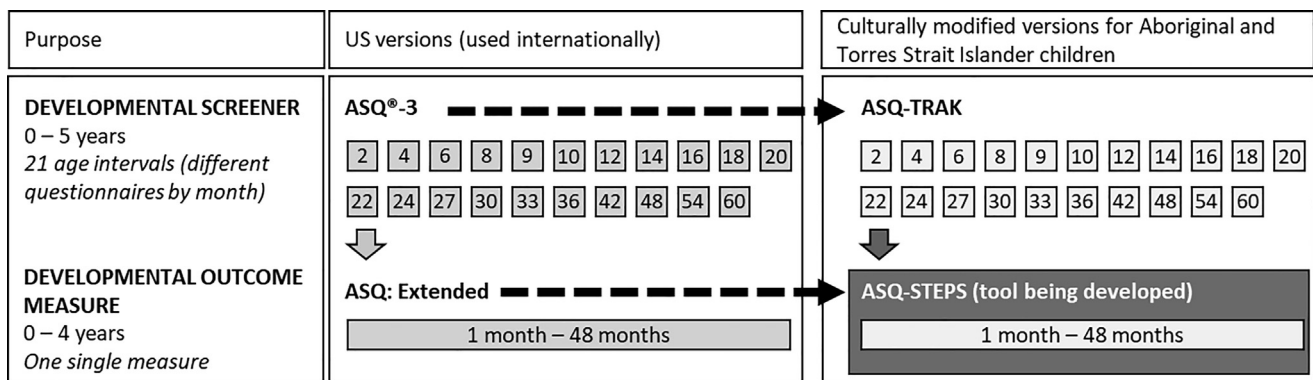


Figure 1: Derivatives of the Ages & Stages Questionnaires®, Third Edition (ASQ-3)® to create the ASQ: Extended, ASQ-Talking about Raising Aboriginal Kids (ASQ-TRAK) and ASQ-STEPS for Measuring Aboriginal Child Development (ASQ-STEPS).

Community (D'Aprano et al. 2020; Johansen et al. 2020) and successful uptake (D'Aprano et al. 2022) of those items for the Aboriginal and Torres Strait Islander peoples, developing a culturally modified version of the ASQ: Extended was a clear choice to address this absence of a culturally appropriate developmental outcome measure. The ASQ-STEPS is the result of this decision.

To develop the ASQ-STEPS, the remaining 68 ASQ-3® items were culturally modified. As in the original ASQ-3® adaptation, Herdman et al.'s (1997) universalist approach was again adopted for the adaptation of the remaining items (Figure 2). This approach assumes that assessment procedures are likely to require adaptation across culture, considering equivalences in terms of conceptual framework, items, semantics, operations, measurement and function (see D'Aprano et al. 2016 for more detail).

Pre-testing as part of the adaptation process

Pre-testing is one of the last stages of the adaptation process and involves administering the prototype of an adapted tool to a small sample of the target population. This allows researchers to evaluate the face validity, readability and quality of the initial

adapted tool prior to a full-scale validation study (DuBay and Watson 2019). It can be thought of as a quality check that picks up any problems with the tool, its design or the way it is administered, and provides an opportunity for those problems to be addressed before commencing more precise validation studies. Authors DuBay and Watson (2019) have developed a framework from their review of the key steps of the cultural adaptation process detailed in existing literature on the topic across relevant fields, including social sciences and public health. They recommend that the pre-testing process should be well documented and that rationales be provided for each adjustment made.

The first step of pre-testing is to administer the pilot version of the assessment tool or intervention (developed in the earlier stages of the cultural adaptation through rigorous forward and back translation) to a small sample of the target population. The sample population should have varying education levels to represent the diversity of the population and may include caregivers whose children are already known to have developmental difficulties (DuBay and Watson 2019). Adjustments to the tool or administration approach can be made during pre-

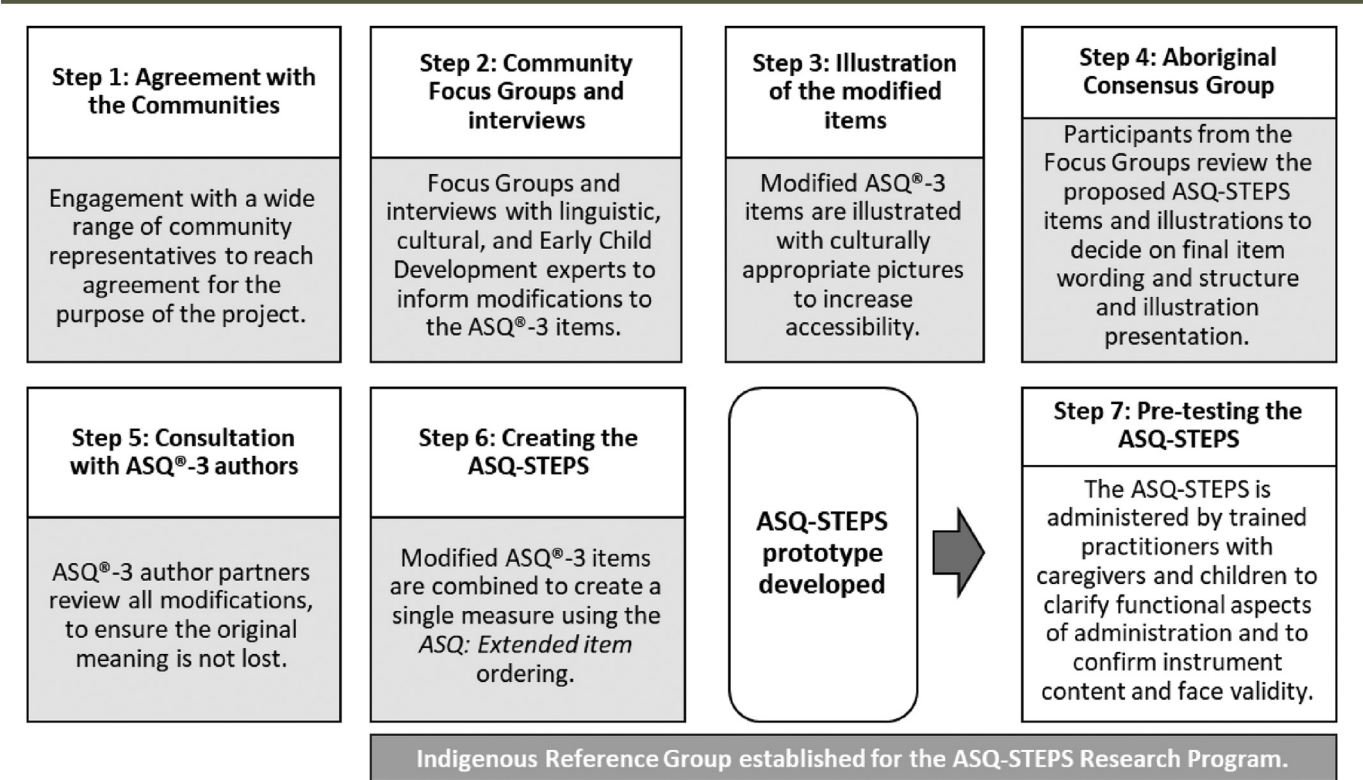


Figure 2: Cultural adaption process. ASQ-3®, Ages & Stages Questionnaires®, Third Edition; ASQ-STEPS, ASQ-STEPS for Measuring Aboriginal Child Development.

testing to address challenges, but these adjustments should be well documented. After administering the pre-testing version, researchers should consult participants to elucidate observational data and explore the acceptability, functionality and appropriateness of the instrument, which would inform further modifications prior to commencing the validation.

This paper aimed to detail the pre-testing phase of the ASQ-STEPS development (Step 7 in Figure 2), clarifying functional aspects of administration and confirming instrument content and face validity, adding to the literature on pre-testing culturally adapted instruments. It aimed to:

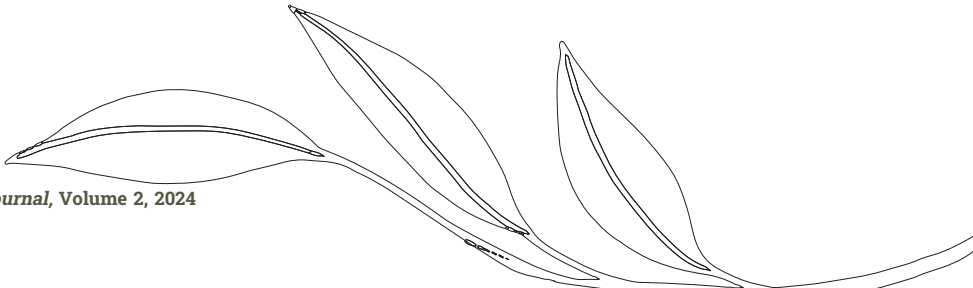
- 1) document the pre-testing process for the ASQ-STEPS prototype

- 2) explore the functionality of the ASQ-STEPS prototype in practice
- 3) explore the acceptability of the culturally adapted ASQ-3® items and accompanying illustrations with caregivers and practitioners in two Australian Aboriginal and Torres Strait Islander communities.

Methods

Methodology

A participatory action research (PAR) approach (Dudgeon et al. 2020) was taken, incorporating the core components of PAR. Participatory action research is an approach that brings together community members and academics to co-create knowledge and social change together. The following governance sections describe this approach.



Governance

An Indigenous Reference Group (IRG) was established for this study to provide leadership on the ASQ-STEPS research program, including advice and guidance. Most of the IRG members were part of the original 'consensus group' (see [Figure 2](#)), which was established to co-create the ASQ-STEPS tool prior to this study commencing. This is what led to genuine interest in remaining involved in and guiding the study, and all but one consensus group member became a member of the IRG.

All IRG members are experts in child development from health and education fields, from different jurisdictions across Australia, who have developed a strong connection with each other and the research team through regular meetings. The IRG co-designed a Terms of Reference with the research team, which included agreement to meet twice a year face to face for half-day to one-day meetings. Unfortunately, travel restrictions during the COVID-19 pandemic meant that some meetings were held via video conference and, on the advice of the IRG, meetings were shorter (1 - 1 ½ hours) but more frequent.

With their knowledge of the tool development, the IRG members played an important role in the research design, reinforcing the need to have a pre-testing phase, rather than going straight to the validation phase, and crystallising the overall purpose and aims of the study. The IRG members are not researchers, and have full-time jobs, so the authors were conscious of not over-burdening them with onerous tasks. However, through the clear Terms of Reference that were co-created, the study was able to establish a process that enabled them to contribute meaningfully. At their request, day-long IRG meetings were held so they could fully engage with the material and provide advice and guidance in person. For example, the IRG provided important

advice regarding which sites and the number of sites to be approached to be involved. They were also involved in guiding consent processes, such as co-developing a pictorial, family information booklet to support caregiver understanding of what study participation required, who was involved, and to ensure informed consent. Findings were presented at the meetings, including this manuscript, so they could be discussed together, and their suggestions incorporated into the draft. Building on existing relationships, ongoing engagement with the partner organisations' research divisions and the Aboriginal staff who worked on the study supported appropriate cultural engagement and responsive implementation approaches for each context.

The IRG members and the Aboriginal staff who worked on the project have co-presented with members of the research team at several conferences and are all included as authors of the manuscript.

Partnering sites

The study was conducted in partnership with two Aboriginal community-controlled health services (ACCHS) who had prior experience with the ASQ-TRAK developmental screener and considered this study a strategic priority. This research collaboration built on existing, strong partnerships between the research team and the ACCHS that were developed over previous collaborations on adaptation studies. The relationship was further fostered through the engagement phase prior to commencement, which enabled the research team to become well known to staff. The ACCHS were in a remote site and an urban site in two Australian jurisdictions and the study was conducted over a two-month period (September to October 2021).

Participants

Purposive sampling was used to recruit practitioners who would administer the ASQ-STEPS. The ACCHS



selected administering practitioners to participate based on their professional role, expertise in child development, and experience using the ASQ-TRAK developmental screening tool in their work with children and families. The ACCHS also identified key staff, such as the Aboriginal liaison officer, who were included as support staff for the project. Caregivers were included (see recruitment below) if they had a child aged between 1 and 48 months, if they identified as Aboriginal and/or Torres Strait Islander, and if they spoke some English. Children were not excluded based on developmental diagnoses. A \$25 gift voucher was provided to caregivers and a book and toy given to the child as a gesture of thanks for their time.

Measures
ASQ-STEPS instrument

As described in detail above, the ASQ-STEPS for Measuring Aboriginal Child Development (ASQ-STEPS) is a developmental outcome measure for Aboriginal and Torres Strait Islander children aged between 1 and 48 months. The ASQ-STEPS is a single measure with 50 to 55 items per developmental domain. This is a family-centred, culturally responsive tool that is designed to be used in a strengths-based way.

To determine the ease of use of each component in the field, different versions of the ASQ-STEPS

prototype were developed for the purpose of pre-testing. As such, administrations were iterative, and practitioners were encouraged to try different combinations of the materials to explore which was most appropriate to facilitate administration and promote child and caregiver engagement. As more was learnt about ASQ-STEPS administration, materials were modified in response to practitioner needs.

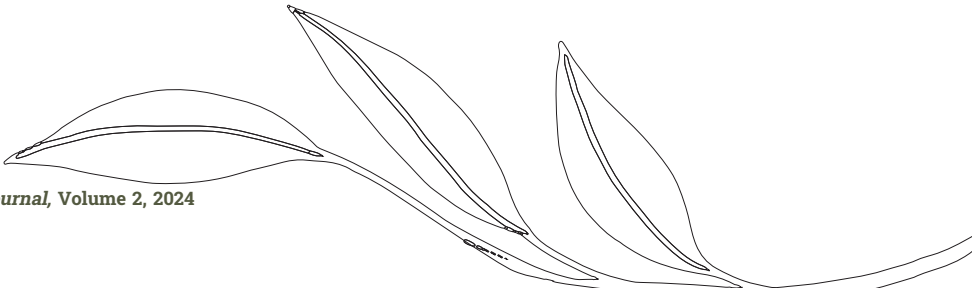
The prototype piloted in this study included different versions of the materials to be trialled for administration and scoring in different combinations (Table 1). Two versions of a booklet (A = all domains combined and B = single domains in each booklet) and two versions of the domain cards (D = limited set and E = complete set) were created. See Supplementary Materials A for images of the materials. An additional separate record sheet (C) was developed for use in combination with either version of the domain cards if the practitioner chose not to use a booklet (which incorporated the record sheet). Practitioners used the materials in different combinations to determine the easiest way to administer the ASQ-STEPS tool with caregivers.

Observation record

A researcher observed each ASQ-STEPS administration and took written notes on the

Ref	Material	Description
A	Booklet - all domains combined	A combined A4 booklet containing all three domains being pre-tested. This booklet included administration notes for the practitioner, the items, illustrations and the scoring area in one document .
B	Booklet - single domains (separated)	An A4 booklet containing a single domain being pre-tested individually . This booklet included administration notes for the practitioner, the items, illustrations and the scoring area.
C	Record sheet (separated)	A separate record sheet (i.e. scoring area) containing a single sheet for each domain. The record sheet only included item numbers and an area to record the score for each item administered in a grid format. The record sheet was for use in administration with the domain cards.
D	Domain cards - limited set	A limited set of three to six A5 cards in a 'concertina' style including the item number, item, illustration and scoring instruction for the item. These domain cards were grouped by age interval and domain.
E	Domain cards - complete set	A ring-bound complete set of A5 cards for each domain. These domain cards included the item, illustration, the scoring instruction for the item and administration notes for the practitioner. Tabs on the right-hand edge of the domain card grouped them by age interval.

Table 1: Description of the versions of the prototype materials trialled by practitioners



observation record (see [Supplementary Materials B](#)). The observation record was developed by LLM (the Aboriginal research assistant), AD and IB. The observation of each administration documented the use of materials, administration support and space, challenges in implementation, duration of the administration, and any other details that could inform the finalisation of the ASQ-STEPS instrument.

Post-administration meeting record

Immediately following the ASQ-STEPS administration, the researchers met briefly with the practitioner to obtain their feedback on the administration process, ASQ-STEPS design, ASQ-STEPS content and the interaction with the child and caregiver. This captured what did and did not work and how this could be replicated or approached differently in subsequent ASQ-STEPS. These structured interviews were recorded on paper (see [Supplementary Materials C](#)) and designed to align with the observation record.

Focus group/semi-structured interview schedules

To collect both practitioner and caregiver perspectives on the functionality and acceptability of the ASQ-STEPS, interview schedules were developed for both focus groups and semi-structured interviews. The schedules were designed by the research team, including LLM, and reviewed by ES.

Procedure Training

At study commencement, participating practitioners attended a three-hour in-service on the ASQ-STEPS developmental outcome measure. Delivered by research staff (IB), this included how to administer and score the tool, using the same strengths-based, culturally-safe approach developed for the ASQ-TRAK training. The training also included other key staff (such as the Aboriginal liaison officer and other

support staff, including author ES), which provided a broader opportunity for strengthening capability in the ACCHS. In addition, the study implementation approach at each site, based on the local context, was discussed and agreed upon. Including the Aboriginal support staff in the training, together with the participating practitioners, promoted community participation in the study.

Recruitment

Due to differences in staffing at the two sites, the recruitment process was customised to best suit the participating program/s at each service.

Site 1: An Aboriginal liaison officer (from the ACCHS) made initial contact with caregivers. The Aboriginal liaison officer explained the study to caregivers, gauged caregiver interest in participating and obtained consent for the Aboriginal research assistant (from the ACCHS) to contact caregivers regarding participation. If the caregiver consented, the Aboriginal research assistant scheduled a suitable time for them to attend an ASQ-STEPS appointment. The Aboriginal liaison officer or Aboriginal research assistant completed the written consent form with the caregiver prior to the ASQ-STEPS or, if preferred by the caregiver, when they attended the ASQ-STEPS appointment. Promotional materials placed at participating programs also enabled caregivers to approach the research team to participate. The practitioners were not involved in the recruitment or consent of caregivers at Site 1. The researchers were present at the ASQ-STEPS appointment to answer any additional questions the caregiver had before commencing the ASQ-STEPS.

Site 2: The Aboriginal child health worker (from the ACCHS) made initial contact with caregivers. The Aboriginal child health worker was also the



administering practitioner of the ASQ-STEPS and had strong connections with the caregivers engaged with the service. The Aboriginal child health worker provided caregivers with verbal and pictorial information about the study and the requirements of participation. If the caregiver agreed to participate, a consent form was completed by the Aboriginal child health worker when the caregiver attended the program for a regular contact point or for the scheduled ASQ-STEPS appointment. The researchers were present at the ASQ-STEPS appointment to answer any additional questions the caregiver had before commencing the ASQ-STEPS.

ASQ-STEPS administration

Following the in-service, a practitioner administered the ASQ-STEPS with the child and caregiver at the health service. For the purposes of pre-testing, only the Fine Motor, Problem Solving and Personal Social domains were administered. This approach was approved by the ASQ author group and deemed appropriate for two reasons: (1) the focus of the study was not to investigate the child data collected about their developmental status but to understand

the process; (2) it reduced the burden of participation on organisations and families, which was an important consideration identified by the partner organisations and IRG. Each administration of the ASQ-STEPS was observed by a researcher (LLM or IB) who completed the observation record. Practitioners were supported by the research team to provide appropriate developmental feedback to caregivers. This aligned with existing developmental monitoring processes at each site and meant that established referral pathways were available should concerns about the child’s development be identified.

The research team (LLM or IB) conducted the post-administration meeting with the practitioner/s immediately following the completion of the ASQ-STEPS, drawing on notes captured in the observation record.

As illustrated in [Figure 3](#), data collected through observation and post-administration meetings were used during study implementation to inform subsequent use of materials in ASQ-STEPS

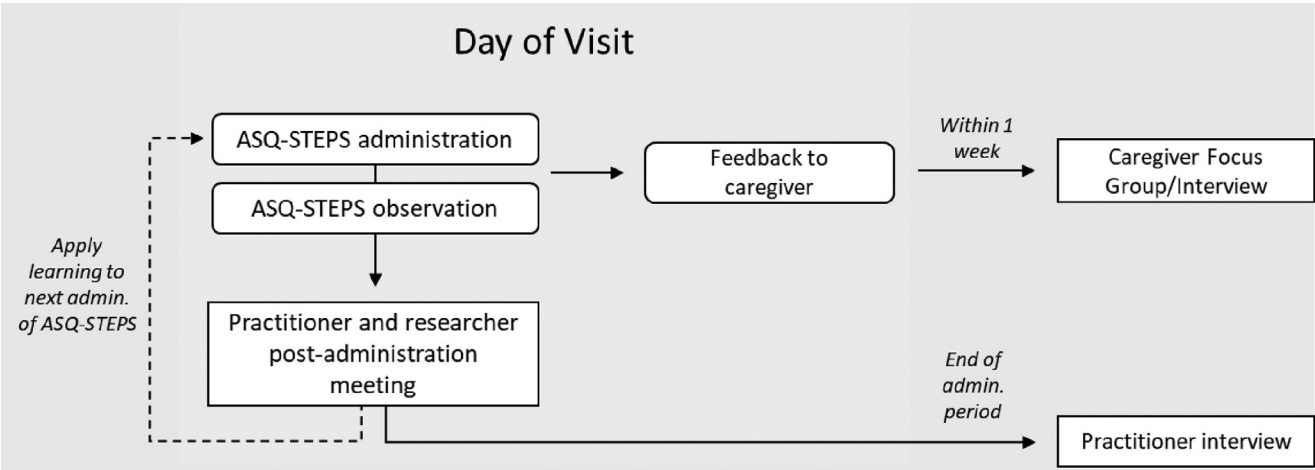
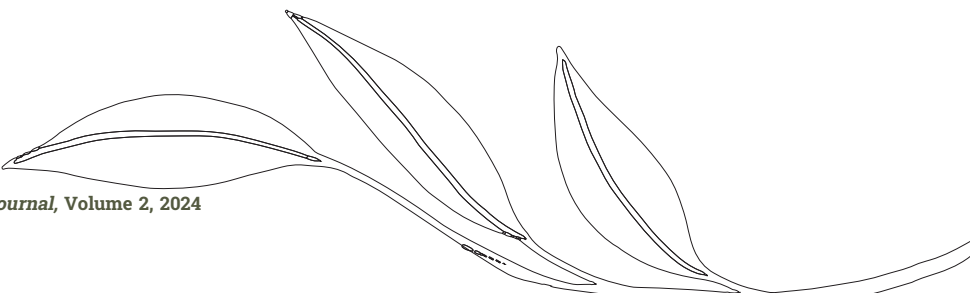


Figure 3: Study procedure. ASQ-STEPS, ASQ-STEPS for Measuring Aboriginal Child Development.



administrations in an iterative process (shown by arrow with a dotted line).

Focus groups/interviews

Caregiver focus groups and interviews were conducted within a week of the caregiver participating in an ASQ-STEPS, at a time that was convenient to them. Focus groups and interviews were conducted face to face or by phone, according to caregiver preference. The Aboriginal research assistant (LLM) co-facilitated all focus groups and conducted all interviews. Practitioner interviews were completed by LLM and IB at the end of the ASQ-STEPS study period, each lasting between 30 and 45 minutes. All interviews were audio-recorded with written informed consent, transcribed by the study research assistant and the transcripts checked by IB.

Focus group and interview data analysis

The thematic analysis of focus group and interview data involved four phases: development of the coding framework, first round of deductive coding of content fitting the coding framework, refinement of the coding framework, and second round of inductive coding fitting the refined coding framework. The Aboriginal research assistant (LLM) was involved in all four phases of the analysis. Then, LLM, IB and the research assistant independently read all the interview transcripts and developed a coding framework using the focus areas of ASQ-STEPS observation records and the practitioner and researcher post-administration meetings. In addition, LLM further reviewed and finalised the coding framework to ensure that it aligned with the research questions and allowed for cultural-related feedback to be adequately captured. Guided by the coding framework, IB and the research assistant each independently coded all the focus group and interview data in MS Word. Coded sections of the transcripts were then examined by IB and the research assistant to reveal any misalignment

of coding between coders and any interpretation issues ([O'Connor and Joffe 2020](#)). Together with IB and the research assistant, LLM refined and added sub-codes to the coding framework until they reached agreement, ensuring centring of the Aboriginal voice. The research assistant re-coded the transcripts using the refined coding framework and the coded data were collated according to themes in a single MS Excel document for the write-up of results and discussion with the IRG. Definitions of each theme were developed.

Ethics and approvals

The study was guided by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics for Aboriginal and Torres Strait Islander research ([Australian Institute of Aboriginal and Torres Strait Islander Studies 2020](#)). Following community engagement and consultation, applications were submitted to the research division of each partner organisation for review and approval. Ethical approvals were obtained from the Central Australian Human Research Ethics Committee (CAHREC-18-3088), Aboriginal Health Research Ethics Committee (Protocol # 04-19-836) and the University of Melbourne Human Research Ethics Committee (Ethics ID 1851554).

Results

Three practitioners participated in the study. At Site 1, a child health nurse and Aboriginal health practitioner. While the child health nurse was non-Indigenous, she had been living and working in the community for many years, with close family connections to community. An Aboriginal child health worker participated at Site 2.

Twenty-six children aged 1 – 53 months (M = 27 months, 23 days) were consented to the study across



the two sites, with 19 completing an ASQ-STEPS (12 female [63%]; 12 at Site 1 and seven at Site 2; see Table 2). Five of the children had identified developmental difficulties. This included a 53-month-old child whose caregiver was keen to be included and provide her perspective on the tool, despite her child being above the 48-month upper age limit. This caregiver was included in view of the aims of this study being to determine acceptability of the tool and the process (rather than accuracy). Children and caregivers who did not attend the scheduled ASQ-STEPS appointment withdrew due to child illness, family commitments or unavailability during the data collection period.

Functionality of the ASQ-STEPS

The design of the ASQ-STEPS materials was explored through observation, post-administration meetings and semi-structured interviews. The practitioners’ approach to administering the ASQ-STEPS evolved over time as they increasingly became familiar with the materials and content. Observation showed a shift from a reliance on the booklet (materials A and B) to almost exclusively administering with the complete set of domain cards (material E) and separate summary score sheet (material C). One practitioner identified the complete set of domain cards as being good to use: ‘They’re like a link between me and the parent... I didn’t use the [booklet].’

Other practitioners commented on their shift in perception of the limited set of domain cards (material D) following an administration:

When we first started that concertina, everyone was like, ohh that’s gonna work so well... yet, when we actually tried it in real-time it was really difficult... it became really... evident that it was harder with them.
(Practitioner 1)

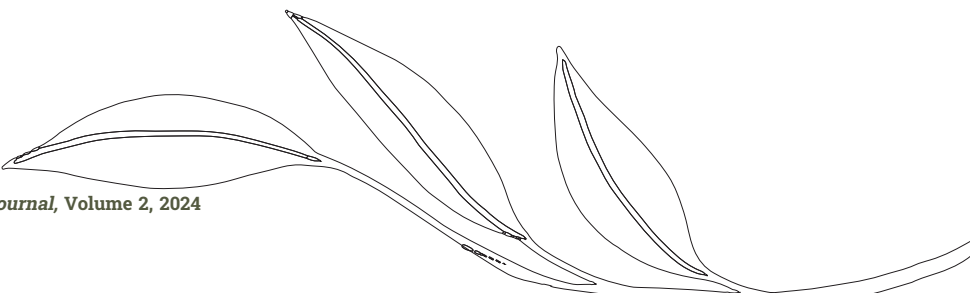
Child	Age (months, days)	Gender	Participating caregiver	Site	Focus group or interview
1	53, 2	F	Mother (C01)*	Remote	Y
2	2, 22	F	Mother (C01)*	Remote	Y
3	27, 2	F	Carer (C02)	Remote	Y
4	28, 26	F	Mother (C01)*	Remote	Y
5	43, 1	M	Mother (C16)	Remote	N
6	42, 11	M	Mother (C03)	Remote	Y
7	28, 4	M	Mother (C04)	Remote	Y
8	43, 6	M	Mother (C05)	Remote	Y
9	36, 10	F	Mother (C06)	Remote	Y
10	37, 27	M	Mother (C07)	Remote	Y
11	39, 18	F	Mother (C08)	Remote	Y
12	8, 12	F	Grandmother (C09)	Remote	Y
13	1, 5	F	Mother (C10)**	Urban	Y
14	36, 29	M	Mother (C11) and Grandfather (C17)	Urban	Y (Mother)
15	20, 9	F	Mother (C18)	Urban	N
16	4, 5	F	Mother (C12)	Urban	Y
17	40, 4	F	Mother (C10)**	Urban	Y
18	3, 29	F	Mother (C13)	Urban	Y
19	30, 9	M	Father (C14) (Mother present for some admin time; C15)	Urban	Y

F = Female, M = Male, *Caregiver of child 1, 2 and 4; **Caregiver of child 13 and child 17
Eighteen caregivers participated, with two caregivers completing the ASQ-STEPS with more than one child, one child completing the ASQ-STEPS with two caregivers in attendance for the whole administration, and one child having both parents present for part of the administration. Of the 18 caregivers, 15 (83%) provided feedback through a focus group or individual interview. The caregivers who did not provide feedback were unable to participate due to child illness or work commitments.

Table 2: Demographic data of children and caregivers

I like the domain cards on a ring. I didn’t think I would because... it’s so bulky... I found that flowed a lot easier with the [complete set] domain cards.
(Practitioner 3)

Caregivers also reported a preference for the use of the complete set of domain cards (material E) in administration. The limited set of domain cards (material D) and the booklets (materials A and B) presented more than one item at once, whereas the



complete set of domain cards were simpler in presentation:

Having the [complete set of domain cards] for each question... makes it a lot easier... the parent can actually sit there, with the staff member asking the question and then be like, 'okay, does my baby actually do this?'... gets [you] to actually focus... instead of having a million things going through [your] mind. (Caregiver 13)

Practitioners identified the record sheet (material C) as the preferred option, with one commenting: 'I like using... the scoring sheet... I much preferred it that way... I just found it flowed better.' (Practitioner 3). The increased visibility of the record sheet (material C) was also seen to support the implementation of basal and ceiling rules required during administration: 'For administrative... it would be easier to use the score sheet so then you could see... if you had to go backwards, because then you could see... quite clearly.' (Practitioner 1).

Acceptability of the culturally adapted ASQ-3® items and accompanying illustrations

Caregivers and practitioners agreed that the content of the ASQ-STEPS was acceptable, and the modified items were clear and easy to understand, with one caregiver commenting that it was surprising that they were all 'decent questions' (Caregiver 6). Most respondents found the accompanying illustrations useful, appreciating that it helped communicate the intent of the item:

So, reading out and then looking at the picture... it was just very descriptive, and you could see what they were thinking... a lot of people are visual learners... (Caregiver 9)

However, practitioners and caregivers identified some repetition among the items within some of the

domains because they targeted the same developmental skill along a progression of development. They made suggestions about how to highlight the differences between items: 'Putting the key words as bold would be easier with picking up with some of those repetitive questions.' (Caregiver 9).

There was value for caregivers in participating in the ASQ-STEPS. Caregivers reported that they found value in completing the ASQ-STEPS because it afforded an opportunity to see their child's abilities but was also educational: 'I thought it was good, just to see like how [child] is tracking along for myself as well... Like, learning new skills, some I didn't know he had.' (Caregiver 4).

The progressions and seeing the items the child was not yet able to do demonstrated how, as caregivers, they could provide further opportunities for their child to learn new skills: 'I'll be able to make sure that... baby is learning things. I can teach him some things... gave me little ideas to do with them, help them develop.' (Caregiver 4).

Caregivers also identified the benefit of their role within the administration process, indicating that supporting them to administer the items with their child was empowering: '... the option for me to ask [the] questions and stuff... I think that's an advantage.' (Caregiver 14) and '... to actually be able to have someone ask me [to demonstrate] that question... and see that she actually does... That was really good too.' (Caregiver 13).

There were also other identified benefits of participating. Some caregivers described that it was a fun, enjoyable activity for the child: '... [Child] said he had fun.' (Caregiver 5)



While some parents did report feeling nervous about bringing their child for an ASQ-STEPS, they were reassured by the process. It was described to be a safe environment where they felt 'alright to ask and discuss':

It is a bit scary sometimes... 'cause you can get like 'Oh what if she's really behind? What am I doing wrong?'. But I felt very... reassured. It wasn't like upsetting. So, I think you guys are great and your attitude towards it [is] great. (Caregiver 12)

Positive feedback was received from practitioners at both sites about the value of the ASQ-STEPS for both them and their clients:

As an overall, it's a really good tool... I could see this in so many spaces. Like I could see this in the NDIS [National Disability Insurance Scheme] space, I could see it in all of those spaces. It would be really, really valuable. (Practitioner 3)

It's still positive... majority of them can see that the child was on track, or that... their concerns were validated... and the engagement and the empowering of it was really great... It'll be very helpful in a lot of areas... think it'll be a really great tool. (Practitioner 1)

Overall, there was agreement between caregivers, practitioners and observers who participated in the pre-testing about the design of the ASQ-STEPS. The ASQ-STEPS was acceptable to caregivers and practitioners, and they reported that the ASQ-STEPS items were clear and easy to understand. Notably, caregivers reported that the administration process felt comfortable and culturally safe.

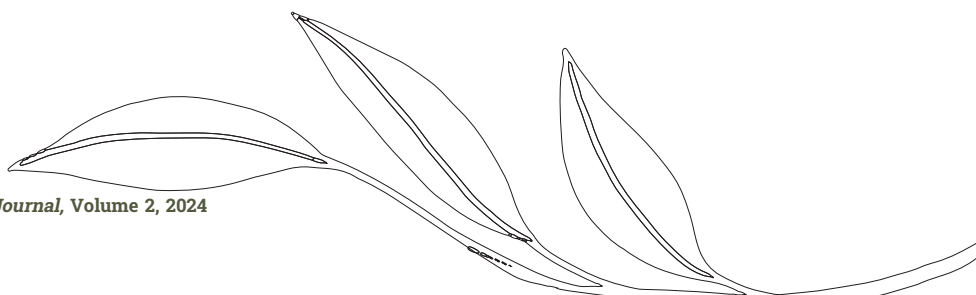
The data from caregiver and practitioner feedback combined with the researchers' observations were integrated and informed changes to the prototype.

These included changes to the administration approach and the items, illustrations and materials that make up the ASQ-STEPS instrument. This is an iterative process that has involved ongoing consultation with additional groups separate to the participants in this study (such as the ASQ author group). The output of this process is the final ASQ-STEPS instrument ready for validation.

Discussion

This study aimed to document the pre-testing process for the culturally adapted ASQ-STEPS prototype. As part of this process, it explored the functionality and the acceptability of the ASQ-STEPS with caregivers and practitioners in two Australian Aboriginal communities. Details of the pre-testing process are provided, adding to the literature in this field. Findings from this pre-testing study have informed changes to the ASQ-STEPS and contributed to the improvements made to the final version for validation.

While the importance of including community stakeholders in the adaptation process is well known (D'Aprano et al. 2016; Dender and Stagnitti 2011; Marley et al. 2017; Tekola et al. 2020), involving the target population in pre-testing is not always part of developmental tool adaptations or translations (Soto et al. 2015). For this study, it was a critical step that enabled multiple options of the ASQ-STEPS design to be tested and discussed before finalising the version for further validation. In this way, the study was able to explore Aboriginal and Torres Strait Islander caregivers' and practitioners' reactions in a real-world setting. This provided greater confidence in the final prototype before proceeding to further validation. Involving the intended users of the tool in the pre-testing, and incorporating their perspectives, is a widely endorsed approach (DuBay et al. 2021; Soto et al. 2015). This is even more critical in this context, where involving





Aboriginal and Torres Strait Islander voices in the research is essential for outcomes that reflect the values, priorities and perspectives of these communities (Harfield et al. 2020). While pre-testing is resource-intensive, it is an essential step that should not be overlooked, particularly in this context.

Adopting the recommendations from the literature, that data collected during the pre-testing phase should inform revisions (DuBay and Watson 2019), caregiver and practitioner recommendations were incorporated into improvements to the ASQ-STEPS and are outlined in Table 3. These recommendations focused on increasing clarity, accessibility and supporting more fluid administration of the instrument for practitioners and caregivers. For example, Recommendation 1 was related to some items appearing the same because they had subtle skill progression. To avoid feeling repetitive, and risking the caregiver becoming disengaged, additional instructions were included to support the practitioner to

communicate the difference. Another improvement, addressed by Recommendation 4, was introduced to reduce the burden on families. Making allowance for the ASQ-STEPS to be administered over two sessions within a 1-week period (that is, break up the administration) provided the caregiver and practitioner options, to optimise engagement and, subsequently, the results.

The ASQ-STEPS prototype was found to be accessible and inclusive of caregivers. While caregivers and practitioners reported that the use of simple language and culturally appropriate illustrations to show the intent of the items support a culturally safe experience, the IRG made further recommendations about how to improve culturally safe developmental assessment (Box 1).

They recommended that supporting staff who have extensive cultural knowledge, strong community roles and experience working with children and families to

Recommendations	Improvements made
1. Highlight how similar sounding items are different.	- Additional instructions for the practitioner, to improve communication. - Key words bolded to show subtle differences between similar sounding items.
2. Remove visible references to the age interval for each item on domain cards (i.e. 24 to 30 months) so caregivers do not feel shame if their child is being administered items from a younger age interval.	Items referenced only by number at the front of the domain card. Information about age interval moved to back of domain card (visible to the practitioner).
3. Move some of the administration information to the back of the domain cards to reduce distraction.	Increased size of domain cards and moved information related to administration approach to back of domain cards. This also allowed for increase in text size for the item.
4. Allow for administration over two sessions within a set time period if service type allows.	Introduction of 1-week window to complete administration if appropriate.
5. Change the order of items if the item related to a more advanced developmental skill appears prior to earlier skill development.	Items re-ordered following consultation with original author group.
6. Develop additional administration instructions and item introductions for individual items identified as challenging.	Additional item administration and item introductions developed and approved by original author group and critical friends.
7. Increase detail and visibility of links between items to support flexible administration.	New instructions about scoring and administration actions developed and added to the back of each domain card to highlight links between items and next administration steps based on child response.

Table 3: Recommended changes to the ASQ-STEPS instrument





Box 1. Indigenous Reference Group recommendations

- Identify appropriate Aboriginal and Torres Strait Islander staff to administer the ASQ-STEPS
- Build capability in the Aboriginal and Torres Strait Islander workforce
- Develop training that meets the needs of the workforce
- Create mechanisms for place-based support

be the leaders in the administration of developmental assessments for Aboriginal and Torres Strait Islander children is a key step towards optimising cultural safety. However, the paucity of Aboriginal and Torres Strait Islander peoples with the qualifications deemed necessary to administer these assessments highlights the need for further efforts. This requires allowing time for comprehensive, appropriate training that builds capability and on-the-ground support to ensure that fidelity of the assessment is maintained. A focus on workforce development is vital to promote cultural safety in developmental assessment, a view supported by the National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031 ([Commonwealth of Australia 2022](#)).

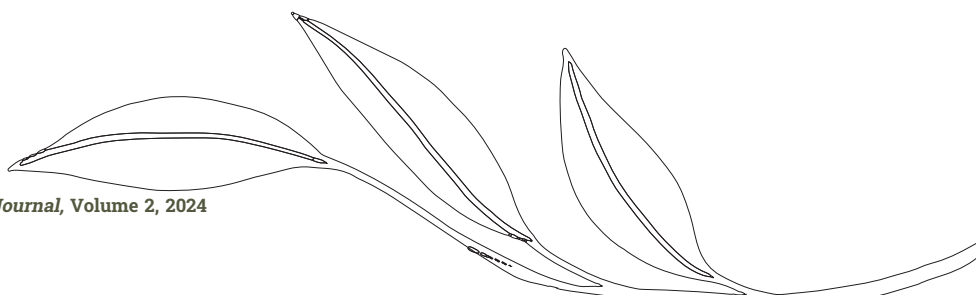
This study has documented the pre-testing phase, providing detail of the prototype testing and detail of the steps taken to agreeing on the final version for validation. However, the practice of reporting on pre-testing processes in publications, as recommended by [DuBay and Watson \(2019\)](#), is variable. While some studies of translation and adaptation of other health tests and interventions outline similar processes to [DuBay and Watson \(2019\)](#), these accounts are often lacking the necessary detail that would allow replication of the methods. In a review of autism

spectrum disorder screening tools, Soto et al. found that two of seven papers that mentioned pre-testing gave a sufficiently detailed account of their pre-testing process, while others omitted it entirely ([Soto et al. 2015](#)). Detailed documentation of the pre-testing process in publications is an important component that improves transparency regarding how the final version was developed and who was involved, and can inform future, similar studies. [DuBay et al. \(2021\)](#) describe the pre-testing step to be ‘the most fruitful step in the process’ (p. 3926) of cultural adaptation of an autism spectrum disorder screening tool ([DuBay et al. 2021](#)).

Summary of limitations and strengths

This study had several strengths. First, it was conducted in both a remote and urban Aboriginal setting in different states of Australia. Second, there was strong governance, with an Indigenous Reference Group established to guide the research from the outset, whose members are co-authors. Furthermore, consent materials were designed with the IRG members’ input to ensure improved communication with participants. Finally, close attention was paid to the cultural safety of participating families. An Aboriginal research assistant was included as part of the research team and an Aboriginal liaison officer was employed in the community to support recruitment of Aboriginal families, to address the cultural safety of participating families.

The study had some limitations. The research staff, who conducted all caregiver and practitioner interviews, were the same staff who had delivered the training and supported the administration of the ASQ-STEPS. Therefore, these relationships may have introduced social desirability bias. However, it was attempted to reduce this bias by ensuring that families and practitioners were fully informed about the aims



of the study – families were recruited to the study by staff well known to them and encouraged to provide honest feedback. Moreover, using an independent researcher to undertake the qualitative interviews would have introduced another barrier. For many Aboriginal families using an external researcher, who was unknown to them, would not be culturally acceptable and likely impact the quality of information. Finally, while there were considered reasons for including three of the five domains as part of this study, there may have been findings specific to those domains that were not captured. While this is a limitation, all five domains will be included in the validation phase of the overall project where this will be explored further.

Conclusion

This pre-testing study found that caregivers and practitioners made several important recommendations for modifications to the culturally adapted ASQ-STEPS. This step has led to an improved prototype ready for validation and highlights the value of engaging and consulting with partners in the pre-testing phase, to better understand the community needs and co-create the final tool. To date, there has been a scarcity of literature providing detailed accounts of the pre-testing process in the cultural adaptation of a child development screening tool or outcome measure. While some studies outside this area have provided a more detailed framework to follow, this study includes a detailed account of the pre-testing process in the Aboriginal and Torres Strait Islander context, incorporating strong Aboriginal and Torres Strait Islander governance, which can be used as an example for future research projects.

Author contributions

A. D'Aprano: Conceptualisation, funding acquisition, methodology, supervision, formal analysis,

resources, visualisation, writing – original draft, writing – review and editing. L. Lindrea-Morrison: Investigation, data curation, methodology, resources, formal analysis, visualisation. E. Stubbs: Investigation, methodology, formal analysis, visualisation. J. Bisset: Investigation. A. Wunungmurra: Conceptualisation, methodology, resources, writing – review and editing. C. Boyle: Conceptualisation, methodology, resources, writing – review and editing. C. Hull: Conceptualisation, methodology, resources, writing – review and editing. J. Campbell: Conceptualisation. M. Naylon: Conceptualisation, methodology, resources, writing – review and editing. R. Brunette: Conceptualisation, methodology, resources. S. Simpson: Formal analysis, writing – original draft. I. Brookes: Conceptualisation, data curation, investigation, methodology, project administration, formal analysis, visualisation, resources, writing – review and editing.

Data sharing

Ethical approval and the contexts where this study was conducted required assurances to participants that their data would not be shared beyond the research team. Therefore, data are not available and the data that have been used are confidential.

Declaration of interests

Anita D'Aprano reports administrative support was provided by Central Australian Aboriginal Congress Aboriginal Corporation and Nunkuwarrin Yunti of South Australia Inc. Anita D'Aprano has been granted permission to adapt the Ages & Stages Questionnaires product line to develop the ASQ-STEPS instrument by Paul H. Brookes Publishing Co., Inc. (Licensor). The Intellectual Property Rights associated with the adaptation remain with the Licensor. If there are other authors, they declare that they have no known



competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Author biographies

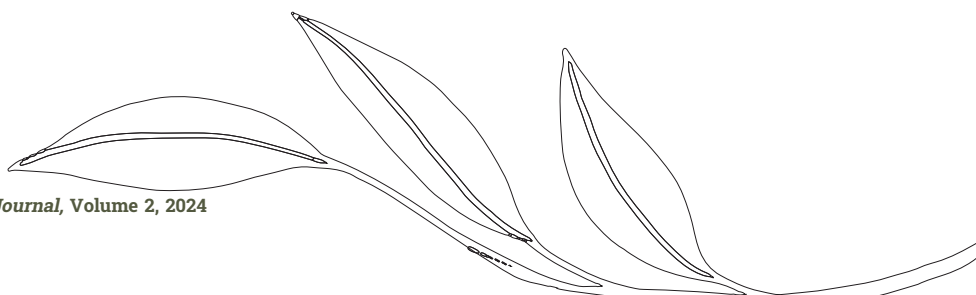
Anita D'Aprano is a developmental paediatrician and principal research fellow at the University of Melbourne. The daughter of Italian migrants, Anita was born and raised on Wurundjeri Country. She lived in the Northern Territory for four years where she undertook her PhD, leading to the creation of the ASQ-TRAK developmental screening tool – the first culturally appropriate tool for use within the Aboriginal and Torres Strait Islander context. Anita has research networks across Australia and is committed to community led, co-designed research that makes a difference to the well-being of Aboriginal and Torres Strait Islander families.

Leah Lindrea-Morrison is a proud Yorta Yorta woman from Shepparton in Victoria. As the Aboriginal research assistant and Community Engagement Officer for STRONG kids, STRONG future she was involved in the research to develop the ASQ-STEPS developmental outcome measure. She worked with communities participating in the research and

supporting engagement across the program more broadly. As an Aboriginal mother, sister, aunty and grandmother, Leah understands the importance of the early years. She wants all Aboriginal kids and families to have access to culturally safe and meaningful resources, so they can have positive early learning experiences and development outcomes.

Emma Stubbs is a Pitjantjatjara, Yankunytjatjara, Arabana and Adnyamathanha woman living on Arrernte Country in Alice Springs. She has more than 10 years' experience working in community services, case management, advocacy and community development roles. Emma works as a Senior Aboriginal Research Assistant at Central Australian Aboriginal Congress and believes that all Aboriginal people are researchers, following a 60,000-year-old framework for sharing Tjukurpa (stories) and knowledge. She worked closely with the research team on the pre-testing study, which gave her insight into how the ASQ-STEPS was developed and strengthened her understanding of the value of the tool.

Jodie Bisset is a proud Arabana/Eastern Arrernte woman and Senior Aboriginal Health Practitioner with experience working in community controlled and government health sectors. At the time the study was implemented, she was one of the administering practitioners employed by Nunkuwarrin Yunti of South Australia Inc. Jodie is currently the Ear Health Coordinator at the Aboriginal Health Council of South Australia and oversees ear health across 11 Aboriginal health services. She is a strong advocate for culturally safe measurement of Aboriginal children's development, that is implemented in ways that celebrates children's strengths and empowers families.





Alison Wunungmurra is a Dhalwangu Yolngu woman from Gapuwiyak in the Northern Territory. She is a qualified teacher, with 20 years' experience working in early childhood education. Alison has been the chair of the ASQ-STEPS Indigenous Reference Group for three years, and views this an opportunity to explore and learn, and to share her perspectives as an educator and a Yolngu woman. The ASQ-STEPS Indigenous Reference Group is important to Alison because it gives her a voice in research that impacts children and families in communities.

Cassie Boyle is from the Walmarnpa and Warumungu people and grew up on Arrernte land in Mparntwe (Alice Springs). She is the Aboriginal Coordinator at the Larapinta Child and Family Centre, NT Department of Education. Cassie has been a member of the ASQ-STEPS Indigenous Reference Group since 2021, and this year has been nominated to become the chair. She has participated in the Indigenous Reference Group to ensure the voices of families are heard, as well as to support services to make sure they are meeting the needs of Aboriginal and Torres Strait Islander communities.

Charmaine Hull is Adnyamathanha – a mathuri. Her mother is from the Flinders Ranges – rock/hill people of South Australia. Her father is of the Arabana, Yankunytjatjara and Arrernte people. Charmaine worked as an Aboriginal Health Worker and Enrolled Nurse before graduating as a Registered Nurse over 20 years ago. She became part of the ASQ-STEPS Indigenous Reference Group because it is important to her that Aboriginal children receive the same early developmental care as non-Aboriginal children, and that Aboriginal parents have this support available to them. Charmaine sees her participation in the Indigenous Reference Group as an opportunity for shared learning.

Jeannie Campbell is a Senior Aboriginal Health Practitioner (Child Health) and her language group is Anmatjere. She has 22 years' experience in the health sector and is currently working with NT Health at Ti Tree Health Centre. Jeannie is a strong member of the ASQ-STEPS Indigenous Reference Group, believing that it is important to have culturally appropriate tools for Aboriginal communities, especially tools that have been designed in a way that makes it easy to translate into language. She firmly believes that the earlier we engage with families about their children's development, the quicker we can help make a difference.

Marjorie Naylor is a Western Arrernte woman who was born in Port Augusta but grew up in N'taria (Hermannsburg) about 125 km west of Alice Springs. In 2014, she moved to Central Australian Aboriginal Congress to work as an Aboriginal Family Support Worker. Marjorie became involved with the ASQ-STEPS research in 2018. She values the opportunity to contribute her knowledge to guide the research team to create the ASQ-STEPS the right way – to create something meaningful and relevant for her community. She values being part of the ASQ-STEPS Indigenous Reference Group because it is an opportunity to learn about research and ways of measuring child development.

Raelene Brunette is a Warumungu/Garrawa woman from the Northern Territory. An Aboriginal Health Practitioner with Sunrise Health Service in Katherine, she considers her role one of the best jobs. Her greatest interest is in improving maternal and child health. She believes this is the key area of practice that can turn around health outcomes for Aboriginal children and families. Raelene joined the ASQ-STEPS Indigenous Reference Group after learning about the ASQ-TRAK developmental screening tool. She is a



strong advocate for culturally appropriate tools, and the Indigenous Reference Group lets her add her voice and the voice of her community.

Sam Simpson is a New Zealander who has lived in Melbourne for the past 13 years. She has also spent several months living and working in remote Aboriginal communities in the Northern Territory, where she completed her PhD research. For her PhD, Sam completed a validation study on the ASQ-TRAK. She is trained as a clinical psychologist and she currently works as a consulting assessor, conducting developmental assessments with children in schools.

Isabel Brookes is the Project Coordinator for the ASQ-STEPS Research Program. She has worked on research projects focused on achieving learning and development equity between Indigenous and non-Indigenous children for nearly 10 years. She began working with communities to develop and pre-test the ASQ-STEPS prototype in 2018, while living in Mparntwe (Alice Springs). Isabel believes that a culturally responsive assessment that engages families in their children's early learning and development is essential; and that the ASQ-STEPS will support services for Aboriginal and Torres Strait Islander children to engage in best practice when promoting children's learning and development.

Supplementary material

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.fnhli.2024.100034>.

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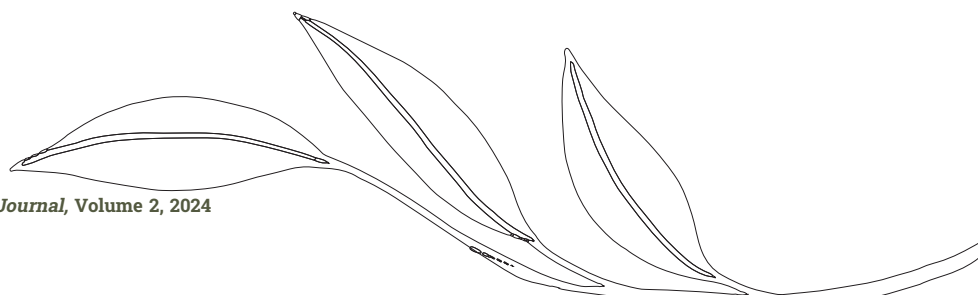
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