

Collaborative Involvement of Indigenous Youth in the Design and Evaluation of Digital Mental Health Interventions: A Scoping Review Protocol

Josie Povey (✉ josie.povey@menzies.edu.au)

Menzies School of Health Research, Charles Darwin University, Casuarina campus, Ellengowan Drive, Casuarina, NT, Australia <https://orcid.org/0000-0001-6961-4674>

Buaphrao Raphiphatthana

Menzies School of Health Research: Charles Darwin University

Michelle Torok

University of New South Wales

Tricia Nagel

Menzies School of Health Research: Charles Darwin University

Fiona Shand

University of New South Wales

Michelle Sweet

Menzies School of Health Research: Charles Darwin University

Anne Lowell

Charles Darwin University

Kylie Dingwall

Menzies School of Health Research: Charles Darwin University

Protocol

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Abstract

Background: Indigenous youth worldwide are at greater risk of developing mental health concerns due to ongoing inequity and disadvantage. Digital mental health solutions are identified as a potential approach to improving access to mental health treatment for Indigenous youth, with evidence of acceptability and effectiveness beginning to emerge. Although collaborative design, development and evaluation is widely recognised as necessary to improving the acceptability of these tools, there is limited evidence to guide engagement of Indigenous youth in these processes. The objective of this scoping review is to map evidence regarding the collaborative involvement of Indigenous youth in the design and/or evaluation of digital mental health interventions.

Methods: Scoping review methodology includes six stages, 1) identifying research question; 2) identifying relevant studies; 3) developing a study selection and data extraction method; 4) charting the data; 5) collating, summarising and reporting results. Additionally, Step 6) consultation, engages a male and female Indigenous health researcher in reviewing protocols, analysis and findings, enhancing credibility and ensuring findings are informed by Indigenous worldviews. Searches for relevant literature are undertaken in the following databases: EBSCOhost databases (Academic Search Premiere, Computer and Applied Science complete, CINAHL Plus with Full text, MEDLINE with full text, APA PsychArticles, Psychology and Behavioural Sciences collection, APA PsychInfo), PubMed, and Scopus. In addition, Infomit and Google (limited to the first 200 results) are searched for grey literature. All primary studies and grey literature in English that meet eligibility criteria are included. Data, including; study methods, methodologies, digital mental health program details, participant information and engagement and reporting processes are extracted and included for analysis. Data extraction variables are guided by the Consolidated Criteria for Strengthening Reporting of Health Research (CONSIDER statement). This statement provides a best practice checklist for reporting research involving Indigenous peoples. This scoping review protocol has been registered with Open Science Framework (available via osf.io/2nkc6).

Discussion: To date, there are no reviews which critically analyse engagement of Indigenous youth in the development and evaluation of youth-specific digital mental health interventions. This review will aim to fill that gap and appraise alignment of current practice with best practice guidelines to inform future research. It will highlight appropriate strategies for the engagement of youth in collaborative processes, providing guidance for health practitioners, policy makers, and researchers working in the field of Indigenous youth and digital mental health.

Background

The majority of Indigenous youth worldwide are resilient, proud of their culture and possess social capital beyond any other recent generation (1-3). Despite this, they remain at heightened risk of developing mental illness in adolescence compared to their non-Indigenous counterparts (4). We use the collective word 'Indigenous' to describe people who originate from a particular region, however, acknowledge the rich diversity and knowledge represented by this term. Despite the need, Indigenous youth worldwide are

less likely to access mental health treatment than non-marginalised young people (5, 6). Barriers to accessing mental health treatment include stigma, fear, shame, intergenerational trauma, distrust of services and being unable to identify signs and symptoms of illness (5, 6). Furthermore, the location of populations in need are often decentralised, meaning long distances, increased costs and challenges in the delivery of services (5, 7). Treatment services are often non-existent, underfunded or occur in a localised or prescribed manner within Indigenous communities, limiting their ability to affect meaningful sustained change. Considerations of language, diversity and worldview differences are sometimes overlooked, resulting in programs that are less meaningful or acceptable to the young people they are intended to serve (8, 9). Despite the need for culturally safe, effective, early intervention treatments, there remains relatively few approaches which are evidence based (10). Recent increased availability of technology and connectivity has been identified as an opportunity to increase access to health services within underserved communities and marginalised youth populations (6).

Digital mental health is identified as “mental health, suicide prevention and alcohol and other drugs services delivered via a digital platform” (11). There remains limited cultural diversity in the digital mental health field, despite recognition of their potential to increase access to treatment for Indigenous populations (12-14). To date, five systematic or scoping reviews have been conducted in the area of health technologies for Indigenous populations (15-19), however only one has focused on youth and mental health interventions (19). One other related article contains a literature review and a case study (20). There is a consensus among the authors of these reviews that meaningful engagement of end users in design, development or evaluation is a necessary component of digital health solutions (15, 17-19). However, none examine in-depth the strategies undertaken to engage Indigenous youth in the design or evaluation process.

Despite the importance of end user involvement in the design and evaluation of digital mental health interventions being widely identified (11, 21, 22), there remains a lack of clear reporting on the methods and processes undertaken (23, 24). A popular methodology outlined in the literature is Participatory Design (PD), which is the involvement of end users in the co-creation and evaluation of digital health resources, as partners (25). This process allows an iterative approach whereby digital resource design is continually reviewed and updated (22), a necessary process which is identified in National Guidelines for safety of digital mental health solutions (11).

Furthermore, ethical guidelines on the conduct of research with Indigenous communities emphasise the importance of cultural considerations when engaging Indigenous youth in research practices (26-29). Engagement of Indigenous youth potentially protects young people and communities from being detrimentally affected and disempowered and allows better opportunity for self-determination (26, 30, 31). A review of ethical standards in Indigenous research, has led to specific guidelines for reporting, such as the Consolidated Criteria for Strengthening Reporting of Health Research involving Indigenous peoples (CONSIDER statement), which aims to improve the quality of research practices involving Indigenous peoples (32). Within this statement, researchers are provided a comprehensive checklist of recommendations which include considerations on the governance, prioritisation, relationships,

methodologies, participation, capacity building, analysis and interpretation and dissemination, of research involving Indigenous peoples. Critically reviewing research practices ensures they uphold ethical guidelines, and safeguards and informs best practice into the future (30).

International research has identified significant strengths unique to Indigenous young people which help build and maintain resilience (33, 34). One such strength is a particular affinity for creative technological innovation and design (15, 35, 36), and willingness to embrace empowerment and self-determination (1). The involvement of Indigenous young people in solutions to address their health needs is therefore as an essential component of health service design and delivery (37). For these reasons it is essential to focus effort on engagement of Indigenous youth in the design and evaluation of digital mental health solutions, to receive the most benefit. This review aims to map evidence regarding the collaborative involvement Indigenous youth in the design and evaluation of digital mental health interventions. Findings will provide recommendations for future projects aiming to collaboratively develop or evaluate digital mental health interventions with Indigenous youth.

Methods

Study Design

Scoping reviews are particularly useful in providing an overview of research on a given topic where evidence is emerging (38) and to review research processes on a given topic (39). For these reasons a scoping review was considered the most appropriate methodology. This scoping review is based on the guidelines proposed by Arksey and O'Malley (40) and the subsequent modifications proposed by Levac et al. (38) and Peters et al. (41). It involves a six-stage process which includes: 1) identifying research question; 2) identifying relevant studies; 3) developing a study selection and data extraction method, which is refined using an iterative process (38); 4) charting the data; 5) collating, summarising and reporting results. Additionally, Step 6) consultation, engages a male and female senior Indigenous researcher throughout scoping review processes, a minimum of three times, ensuring analysis and findings are informed by Indigenous worldviews. Given the iterative nature of a scoping review, changes to the protocol can be expected (41), and any changes are detailed and justified in the final reporting.

Protocol

The protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P) statement (see supplementary file 1). This scoping review protocol has been registered with Open Science Framework (available via osf.io/2nkc6), as scoping review protocols are not currently accepted on PROSPERO.

Research question

The objective of this review is to map evidence regarding the collaborative involvement of Indigenous youth in the design and/or evaluation of digital mental health interventions. More specifically it aims to determine:

- Which strategies, processes and methods are used to include Indigenous youth in the design or evaluation of digital mental health interventions?
- Did strategies, processes or methods used to engage Indigenous youth in design or evaluation of digital mental health interventions align with best practice guidelines?

Eligibility Criteria

Type of studies

All study designs are included. Reviews and opinion pieces are used for reference searching only and not included in analysis. If full text articles are not available, corresponding authors are contacted. The emergence of the internet in the mid 1990's provided opportunities for health professionals to explore alternatives to face to face care (42), and literature on tele-psychiatry appeared not long after (43). Therefore, studies reported from January 1st 1990 to August 31st 2020 are eligible. Only studies reported in English are included due to limitations on time and resources.

Participants

Studies involving Indigenous youth, originating from Australia (Aboriginal and Torres Strait Islander), New Zealand (Maori), Canada (Inuit, First Nations people) and the United States of America (First Nations people) are eligible for inclusion. Indigenous people in these developed first world countries have experiences of colonisation, persistent health inequities and predominantly remote and rural residence. In addition, Indigenous people's health worldviews, language and cultural needs differ from mainstream populations. Youth for the purposes of this review, refer to those who are aged 10-24 years, representative of a broader definition of adolescence, as described by Sawyer et al. (44).

Intervention

Digital mental health interventions 'provide treatment and support to people with mental health disorders through telephone, mobile phone, computer and online applications, and can range from the provision of information, peer support services, virtual applications and games, through to real time interaction with trained clinicians' p.7 (45). Studies focused on developing or evaluating all digital mental health interventions are eligible. Electronic health or medical records, decision support tools for clinicians, analytic services, services that primarily provide support and education to health professionals, clinical practice management software, and clinical workflow and communication software are excluded (11).

Outcomes

There are two broad categories of outcomes that are of interest, 1) study methodology and methods and 2) processes which increase engagement, governance, prioritisation, relationships, participation, capacity, analysis and interpretation and dissemination, as per the CONSIDER statement described earlier (32).

A full list of inclusion and exclusion criteria is included in Table 2.

Table 2: Inclusion Criteria

| Inclusion Criteria |
|---|
| <ul style="list-style-type: none">• Studies where at least 50% of participants are identified as Indigenous, or studies where Indigenous data is identified separately• Studies where at least 50% of participants are aged 10-24, or where data is identified separately for age• Indigenous young people of Australia, Canada, New Zealand, United States of America• The use of Information Communication Technology (smartphone, telephone, iPad, websites, computers and other digital devices) to deliver interventions targeting mental health (can be used for health promotion/psycho-education, prevention/early intervention, crisis intervention/suicide prevention, treatment, recovery and mutual/peer support)• Primary focus of the study is mental health problems and/or wellbeing outcomes, including suicidality, substance use, and smoking. |
| Exclusion Criteria |
| <ul style="list-style-type: none">• Not related to mental health/wellbeing (i.e., physical health needs as outcomes)• Non-Indigenous population or Indigenous population but not from identified countries• Young people are not involved in design or evaluation or are not the intended target audience of the resource• Non-English language due to limitations in time/resources• Electronic health or medical records, decision support tools for clinicians, analytic services, services that primarily provide support and education to health professionals, clinical practice management software, and clinical workflow and communication software |

Search methods and identification of studies

Search Strategy

Following recommendations by Joanna Briggs Institute (46) a three step search process is used. First, two independent reviewers (JP, BR) undertake a limited search of the databases (EBSCOhost and PubMed). Search terms and pilot database search results are shown in supplementary file 2. Titles, abstracts and keywords of retrieved articles are reviewed to find additional search terms, before three reviewers (JP, BR, MT) meet to finalise keywords. Updated search terms are then used by two independent reviewers (JP, BR) to conduct a second search across all databases, including those aimed at identifying grey literature. Databases include; EBSCOhost databases (Academic Search Premiere, Computer and Applied Science complete, CINAHL Plus with Full text, MEDLINE with full text, APA PsychArticles, Psychology and Behavioural sciences collection, APA PsychInfo); PubMed; Scopus; Informit and Google (limited to the first 200 results). Lastly, reference lists of potential studies and reviews are examined for additional studies. If full text is not available, corresponding authors are contacted.

Study selection

The search is performed by two reviewers (JP, BR), who independently review article titles and abstracts and apply inclusion and exclusion criteria outlined in Table 2. If a study's eligibility is unclear, reviewers review full text and apply inclusion and exclusion criteria. Reviewers meet to discuss abstract screening and selection of articles. A good inter-rating agreement kappa is established at the title/abstract review stage, with two reviewers reviewing a minimum random sample of 25 studies, before proceeding to full text review. Once agreement is reached, full text articles are retrieved, and reviewed by two reviewers independently, again assessing eligibility. A final list of included articles is prepared by each reviewer. If consensus is not reached throughout each stage (abstract screening/full text review) of study selection, a third reviewer (MT) reviews the articles in question. Notes are taken describing decisions for inclusion or exclusion.

Data extraction

Two independent reviewers (JP, BR) extract relevant data. If data is missing upon review of full text, corresponding authors are contacted. Data extraction variables, outlined in Table 4, are converted into simple tables prior to data extraction. Data extraction forms are independently tested by two reviewers (JP, BR) on a random sample of five studies to ensure accuracy, consistency and validity of captured information (38, 46).

Table 4: Data Extraction Variables

| Variable | Description or example |
|--|---|
| Study details | Authors, date, title, journal, volume, issue, pages, country of origin, aim/objective of study |
| Description of the digital mental health resource | Purpose, technology type, target population, service type, therapeutic basis, mode of delivery |
| <i>Variables relating to processes undertaken</i> | |
| Stage of development or evaluation | e.g. predesign (formative), early design, post first prototype, feasibility, efficacy or effectiveness trial, community implementation |
| Methodology used | e.g. participatory design, phenomenology, co-design, pilot study, randomised controlled trail |
| Participant demographics | e.g. age, gender, ethnicity, languages spoken, English proficiency, diagnosis, role (i.e. student, patient, carer, health professional type) |
| Advisory boards | e.g. leadership team, research group, consumer group |
| Data collection | Number and duration of design or evaluation sessions, sample size, sites of data collection (e.g. School, community service), methods used (e.g. focus groups, workshops, interviews), support personnel included in design or evaluation processes (e.g interpreters, support staff) |
| <i>Variables relating to research best practice</i> | |
| Justification for project and source | e.g. literature, previous formative study or pilot |
| Participant feedback on design or evaluation processes | e.g. exit interview data, or rating scales of acceptability |
| Author reflections on design or evaluation processes | Reported results, strengths, limitations and recommendations |
| Research team experience in health research | Qualifications, time, reported relationships, credibility |
| Training or support provided to Indigenous research participants | e.g. provision of tablet devices to test products, training in suicide prevention to aid design processes |
| Adaptions in processes in consideration of the physical, social, economic and cultural environment of participants | e.g. ethics amendments to include community consent processes, adaptions to include interpreter following initial visit or recommendation |
| Ethics board clearances | e.g. Indigenous health research ethics committees |
| Partnerships with Indigenous corporations or communities | e.g. Memorandum of Understandings, negotiation processes, agreements reached, approvals or agreements with location specific health or governance boards |

| | |
|--|---|
| Rationale of methods/methodologies used | e.g. literature, previous research, alignment with Indigenous worldviews |
| Consent processes reported | e.g. individual, parent or collective consent, online or face to face, parties involved in consenting process (interpreter, support person) |
| Dissemination practices | To whom, when, platforms used |
| Indigenous involvement in stages of research | e.g. study design, funding, implementation, analysis, dissemination |
| Reporting and analysis which considers the physical, social, economic and cultural environment of the participants | e.g. consideration of social determinants of health, strengths-based reporting |

Collating, summarising and reporting results

Relevant references are exported into Endnote X9, including full text. Endnote X9 allows reviewers to collaboratively manage duplicates, group and code references and add annotations and notes. General inductive analysis is used to determine themes from the data (47). Themes are independently generated and categorised by two reviewers (JP, BR). Revision and refinement of themes occurs within the research team through a series of meetings.

Consultation

Emerging themes and preliminary findings are documented and used to create discussion with two Senior Indigenous Research Officers, on at least three occasions. Preliminary findings prompt discussion and written notes are taken during consultation meetings (38). Consultation findings are presented in final reporting. This consultation phase, originally outlined by Arksey and O'Malley (40) and later refined and defined as necessary, by Levac et al. (38) enhances rigour and provides additional sources of information, perspectives, meaning, and increases the applicability of research findings. Discussion between consultants and the research team refines themes, aiming to reach consensus on results and findings.

Discussion

This scoping review aims to provide a comprehensive overview of current practices and strategies described in the literature regarding the collaborative involvement of Indigenous youth in development or evaluation of digital mental health interventions. Researchers, clinicians and technology developers will benefit from these findings as they assist in establishing best practice processes for engagement of

Indigenous youth in digital mental health approaches as well as health research more broadly. As no other review has previously examined processes of development or evaluation in depth, this review aims to assist researchers to determine the 'how' and develop clear methodology for respectful and culturally safe engagement with Indigenous youth.

List Of Abbreviations

CONSIDER Consolidated criteria for strengthening reporting of health research involving Indigenous peoples

PD Participatory design

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Availability of data and materials

The materials supporting the article is included as Additional files 1 and 2.

Competing interests

The authors declare no competing interests.

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Authors' contributions

JP designed and wrote the manuscript. BR, KD & MT helped design and edit the manuscript. TN, AL, MS & FS provided advice, reviewed and revised the manuscript. All authors read and approved the final manuscript.

Authors information

JP, BR, MS, KD, TN work at Menzies School of Health Research. FS, MT work for Black Dog Institute & University of New South Wales. AL works at Charles Darwin University. Collectively the research team have extensive experience in Indigenous Health Research, digital mental health and qualitative research methods.

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