

A new path to address health disparities: How older Aboriginal & Torres Strait Islander women use social media to enhance community health (Protocol)

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Abstract

Background: Digital health offers a fresh avenue to address health disparities experienced by Aboriginal and Torres Strait Islanders. Despite the scant evidence about how Aboriginal and Torres Strait Islanders access and use health technology, the Australian government has prioritised research that uses technology to enable people to manage their health and promote better health outcomes. Older Aboriginal and Torres Strait Islander women are cultural leaders in their communities, enabling them to provide valuable insights about the safety and efficacy of health care messaging. However, no research has engaged older Aboriginal and Torres Strait Islander, women as partners in digital health research.

Objective: This paper provides a protocol for co-designed translational research that privileges older Aboriginal & Torres Strait Islander women's cultural expertise to design and test a framework for accessible, culturally safe and feasible digital health technologies.

Methods: This mixed-methods research project will use the collective impact approach, a user-centred, co-design methodology and yarning circles, a recognised Indigenous research methodology. A series of yarning circles with three different communities will elucidate enablers and barriers to access health information; co-create a framework clarifying what works and does not work for digital health promotion in their communities; and test the framework by co-creating three digital health information programs.

Conclusions: Privileging the cultural expertise of older Aboriginal and Torres Strait Islander women will provide a novel perspective and vital guidance that end users and developers can trust and rely upon to create and evaluate culturally safe and efficacious digital health promotion programs.

Keywords

Digital health, Aboriginal, Torres Strait Islander, Indigenous, social media, health disparities, co-design, cultural safety, cultural determinates of health, user-centred design, social networks

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Introduction

Technology innovation is revolutionising health and medicine. The World Health Organisation has cited the rapid advances in digital health technology as having the potential to provide cost-effective care to remote and underserved populations.¹ Likewise, the Australian government has prioritised research that uses technology to enable Aboriginal and Torres Strait Islander people to manage their health and promote better health outcomes for their communities.^{2,3} Improving health outcomes is important ¹Centre for Global Indigenous Futures, Macquarie University, New South Wales, Australia

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Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (https://creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access page (https://us.sagepub.com/en-us/nam/ open-access-at-sage). because Aboriginal and Torres Strait Islander people experience significant health gaps compared to the broader population, including dying from avoidable causes at three times the rate of other Australians.⁴ Digital health technology offers a new path to address these disparities. However, accompanying this opportunity is evolving threats created by misinformation or misuse of digital health information. Moreover, access to hardware and Wi-Fi is not equitable in Australia, including access and affordability, particularly for people relying on month-to-month pre-pay data plans. Finally, these harms are amplified by systemic racism that has historically informed the design of western health systems and practices and has dictated the definition of good health and what is necessary to attain it.

It is a matter of ethical urgency that we ensure that innovations in digital health do not perpetuate or exacerbate the socio/political barriers that have contributed to health disparities experienced by Aboriginal and Torres Strait Islander people in Australia. The myriad of social/political factors that impact the health and well-being of Aboriginal and Torres Strait Islander people is well-documented and essential to keep in mind as we evolve digital health technology. Some of the social/political factors impacting Aboriginal and Torres Strait Islander health include racism and marginalisation⁵⁻⁷; entrenched inter-generational trauma⁸; discrimination⁹; inequalities in society¹⁰; disconnection from community and country⁵ the historic and ongoing effects of colonisation^{5,6,8} which contributes to distrust and subsequent reluctance to access services.¹¹ In addition, factors specific to the health system include lack of access to health care services¹²; inadequate access to culturally competent health carers 6,13 which contributes to low trust and a reluctance to ask questions or even seek health services¹¹ creating additional barriers to self-management. These factors and others have led to the normalisation of premature death⁸ and the inevitability of disease.^{8,12,13}

Moreover, inadequate public health communication creates a significant barrier to the utilisation of services.⁷ Communication that is not culturally safe (i.e. is insensitive to an individual's cultural needs, diminishes the person's ability to raise concerns,¹⁴ disempowers cultural identity or does not recognise the colonising context as significant¹⁵) may impact health literacy which is associated with lower engagement in prevention services and practices, higher hospital readmission, poor understanding and adherence to medical advice and lower health self-management.¹⁶ These studies highlight the value of stronger, culturally competent communication and an urgent need to eliminate these health and well-being barriers within the health system.

Crucially while ensuring we do not minimise or neglect to address these negative factors and recognising that racism and ongoing effects of colonialism continue to impact the health of Aboriginal and Torres Strait Islander people, we must shift from an exclusive focus on deficits and barriers to an asset-based lens. This shift in focus is in keeping with the Lowitja Institutes' research^{17,18} which emphasises the protective role of culture. For example, Salmon et al.¹⁷ identified six key cultural domains associated with health and well-being for Aboriginal and Torres Strait Islander people: connection to country; Indigenous beliefs and knowledge; Indigenous language; family, kinship and community; cultural expression and continuity; and self-determination and leadership. Other studies have demonstrated that positive cultural factors such as connection to country¹⁹; emphasis on family and community relationships, and physical expressions of culture²⁰ contribute to Aboriginal and Torres Strait Islander health. Moreover, recent participatory action research projects have identified and leveraged positive factors within health care programs, often building on community assets to strengthen clinical and prevention services. Specifically, recent studies have identified the beneficial role of explicit recognition and celebration of culture embedded as a central precept of health programs^{8,12}; incorporation of fluid, non-linear, time-insensitive, flexible program delivery⁸; focus on self-responsibility and empowerment.^{6,8} Aboriginal health care providers have similarly noted the essential need for patient-centred care that incorporates and honours Indigenous knowledge; ways of being and doing.⁶

Taken together, these findings highlight the fundamental need to incorporate local culture, build on local community resources and point to the criticality of centring Aboriginal and Torres Strait Islander voices from inception through the implementation of all digital health and health communication programs. Moreover, the shift to digital health provides an avenue to proactively shape and fundamentally shift the overall approach to health.

Aboriginal and Torres Strait Islanders are early adopters and active users of technology. Taylor²¹ found 60-80% of residents of one remote community over age ten reported owning a mobile phone and using it regularly. In a 2016 review, Rice found despite the range of living situations across Australia, Aboriginal youth in particular prioritised the use of social media, including Facebook.²² Carlson and Dreher noted that active use of social media facilitates Aboriginal and Torres Strait Islander people to connect locally, nationally and globally, providing cultural connectivity and visibility to Aboriginal and Torres Strait Islander issues never before available.²³ Likewise, social media has also been a catalyst for innovation by Aboriginal and Torres Strait Islander people. For example, Carlson and Dreher²³ has highlighted the synergy between Aboriginal and Torres Strait Islander culture and innovation, explicitly noting innovation in using social media for empowerment and political purposes. Fundamental values and practices of Aboriginal and Torres Strait Islander people such as connection, self-determination and empowerment are also underlying tenets of a digitally connected world.

The Aboriginal and Torres Strait Islander health sector was an early adopter of social media for advocacy, public health promotion and community development.²⁴ Aboriginal and Torres Strait Islander adults engage with e-health tools to address various health issues, including nutrition, smoking and mental health.^{25–28} Carlson et al.²⁹ identified five types of help-seeking related to health and well-being, including soliciting support and information; joining health-related groups; using direct messaging; sharing inspiring content and seeking formal sources of health information. McPhail-Bell et al. highlighted the importance of building community online and offline and the value Aboriginal and Torres Strait Islander people placed on flexibility, trustworthiness and cultural appropriateness in determining the platform's usefulness.³⁰ In analysing the small body of social media health promotion research that includes Aboriginal adults, Carlson et al.²⁹ suggested that social media was a potential avenue for health promotion that was accessible and respectful of Aboriginal and Torres Strait Islander ways of being, they noted themes that reflect principles of reciprocity, selfdetermination, relationality, culture protocol and cultural strength. In keeping with Carlson et al.²⁹ observations regarding the synergy between social media and Aboriginal and Torres Strait Islander ways of being, Rice et al. in a recent review of the literature, identified several themes related to how and why Aboriginal and Torres Strait Islander young people use digital technologies, including community connection, identity, power and control. The cultural compatibility of social media, specifically the multimedia nature of the medium and its compatibility with orally and visually focused cultures, was also noted as a reason for Aboriginal and Torres Strait Islander youth's high usage.²²

Elders and older Aboriginal and Torres Strait Islander people are trusted and respected in their communities. They have traditionally and continue to play crucial roles in transmitting cultural knowledge and tradition.³¹ Older Aboriginal and Torres Strait Islander people have adapted to contemporary circumstances, investing time and effort to help their communities in ways that impact health and well-being, including role modelling, instilling and shaping identity, building resilience and educating and supporting young people.³² Busija et al.³³ identified seven roles of Elders in their communities: caring for youth, safeguarding identity, building community resources, passing down knowledge, community relations, intergenerational connectedness and dealing with racism. Moreover, Warburton and Chambers³² highlighted critical roles for women in shaping and maintaining culture and influencing younger people through sharing stories, role modelling, direct care and identity formation, including links to country, language and knowledge of dreaming.

The way knowledge is passed down and shared both broadly and specifically in Aboriginal and Torres Strait Islander communities are changing rapidly. Advances in technology and electronic sources have become a central source of health information. As early as 2003, Eysenbach and Kohler³⁴ found close to 5% of all internet searches were health-related. Reliance on the internet for health information accelerated during the COVID-19 pandemic. For example, Du et al.³⁵ found searches for health-related information were associated with increased prevalence of COVID-19 in those communities. Information sharing was also prevalent during the pandemic, with Rovetta and Bhagavathula³⁶ finding over two-thirds of Instagram users using COVID-19 and coronavirus as hashtags to disperse health-related information.

During the pandemic, research focused on the role of social media in health also increased. Still, only a tiny proportion of that research explored the efficacy or safety of disseminating health information. For example, in a recent scoping review exploring the roles social media played during the first year of the pandemic, Tsao et al.³⁷ found that 59% of the studies in their review focused on assessing public attitudes. Less than 25% of the studies in this review examined the dissemination of COVID-19-related information. Less than 10% investigated the quality of recommended prevention behaviours. Although several papers in this review identified contributions social media made to disseminating helpful information, many of these studies identified various harms, including misinformation, fake news, conspiracy theories, racism and ageism. Several of the globally based study populations cited in this review included Australian users. However, only one of the 81 articles reviewed in this scoping review specifically identified Australian users, and Aboriginal and Torres Strait Islander people were not mentioned in this paper.³⁸ In another scoping review, only five studies examined the impact of social media campaigns on Aboriginal and Torres Strait Islander health.³⁹ Despite the paucity of studies, Walker et al. noted a consistent theme of self-empowerment. They highlighted the importance of end users, researchers and funders co-creating programs to improve the health of Aboriginal and Torres Strait Islanders. They also noted the need for research and the development of social media health promotion programs that incorporated Aboriginal and Torres Strait Islander perspectives and culture.³⁹

Despite the accelerated uptake of all types of digital health technologies, research examining what is working, not working and why is inadequate. We do not understand how to effectively deliver healthcare messages for Aboriginal and Torres Strait Islander people via social media.

This gap is significant because of the rapid expansion in the use of social media for health promotion. Moreover, forced lockdowns during the COVID-19 pandemic have rendered accessing health information online essential. Furthermore, there is clear evidence that integration of culture is associated with health program effectiveness, but unfortunately, there is a long history of healthcare messaging being created without the input of cultural experts. Aboriginal and Torres Strait Islander women's strong influencing and cultural leadership role in their communities³¹ and as Indigenous influencers on social media,^{24,40,41} positions them to provide valuable perspectives and insights associated with the safety and efficacy of health care messaging. However, no research has specifically engaged Aboriginal and Torres Strait Islander women as consultants or partners in assessing cultural safety or the effectiveness of social media health promotion programs.

Further work is needed to understand which types of messages and which platforms are most effective and why to shape health-promoting behaviour. This study will address these gaps by prioritising older Aboriginal and Torres Strait Islander women's cultural expertise and position within their communities to design and test a framework for assessing and developing culturally safe and digital health programs.

Purpose and Aims: This project will test the hypothesis that older Aboriginal women can and do use technology to enhance health knowledge in their communities.

Aims:

- 1. To understand how Indigenous women in high income countries use social media to inform and influence the health of their communities (method: systematic review)
- To identify how Australian Aboriginal women use social media to inform and influence the health of their communities (method: yarning circles and thematic analysis)
- 3. To develop a working model of how Australian Aboriginal women use and could use social media to inform and influence the health of their communities (method: yarning circles and thematic analysis)
- 4. To test and refine the model using three case studies linked to existing co-design work with Australian Aboriginal communities (method: yarning circles, surveys, data analysis)

Methodology

This mixed-methods translational research protocol will be conducted over two years and includes two parts: part one – Co-identify and co-develop a framework crystalising co-produced knowledge and part two-Test and refine the framework using three case studies. This protocol has received ethics approval, includes Aboriginal and Torres Strait Islander governance, uses collective impact a decolonising methodology and yarning circles a recognised Indigenous research methodology.

Ethics

This protocol has received ethics approval from The Aboriginal Health & Medical Research Council (AH&MRC) on 1 December 2021 # 1862/21.

Aboriginal and Torres Strait Islander governance

Health research methodology has historically disempowered Aboriginal and Torres Strait Islander people. It has marginalised or completely excluded Aboriginal and Torres Strait Islander ways of thinking, learning and doing science. Likewise, community priorities have not informed the direction of health research, resulting in programs that don't meet the community's needs.

The inflexion point created by the shift to digital health is an opportunity to significantly upgrade the way we do health research by incorporating Aboriginal and Torres Strait Islander governance into all health research projects. To this end, we will establish an Aboriginal Project Governance (APG) group in each of our three research communities. We will ask for volunteers from the community to serve as APG members, with the only criteria being that they are members of the community and interested in participating in the governance of this research project. An Aboriginal or Torres Strait Islander woman who is a member of the community will chair the APG and will be paid for her time. The APG chairwomen will be required to have experience in facilitating online group discussions and will be made aware of the time commitment associated with the APG chair role. She will facilitate monthly meetings and have a rolling set of responsibilities such as: clarifying community-specific needs, advising on ethics and participant recruitment and ensuring culturally competent verbal and written informed consent for each participant. The APG chairwomen from each of the three communities will meet regularly via video conference initially to refine the high-level questions we will use in the yarning circles and to agree on the overall approach to facilitation of the varning circles. Ongoing video meeting with the APG chairwomen will include discussing progress, concerns, reviewing consolidated data summaries and providing joint input to the research team. In addition, reviews from the APG chairwomen of all research summaries, papers, and presentations will be provided to the each of APGs for validation before dissemination.

Collective impact

This mixed-methods research will use *collective impact*, a decolonising methodology that prioritises Aboriginal and Torres Strait Islander perspectives. Collective impact uses a structured process to promote community engagement and leadership from inception through implementation and completion. Collective impact has been validated with Aboriginal communities for health program design and research.^{42,43} There are three preconditions for collective impact: (1) Influential community champions; (2) complex problem; and (3) an understanding of why the existing solutions are not working. Once these are met, the process of interpreting evidence through a cultural

lens and bringing together knowledge and expertise to develop, implement and evaluate solutions begins. Collective impact comprises five elements: (1) establish a common agenda; (2) agree on measurement; (3) mutually reinforcing activities (4) continuous communication and (5) backbone support, as illustrated in Figure 1.

Together these five elements facilitate the synthesis of diverse perspectives to develop innovative approaches to address complex challenges that have previously eluded solutions. In addition, the collective impact approach enables researchers to incorporate Indigenous research techniques that are culturally safe, accessible and effective for all stakeholders, including yarning circles. method for qualitative research.^{44,45} A yarning circle is a discussion group whereby facilitators pose questions for consideration and exploration, including reframing and reinterpreting the questions themselves. The format will be a series of questions posed by the facilitators to the group allowing for a non-structured discussion among the group members. As illustrated in Figure 2, successive iterations of yarning circles followed by data consolidation will ensure that everyone agrees about what we have found in each stage before moving on to the next stage.

Research communities

Yarning circles

We will use *yarning circles* as a key technique to collect, analyse and interpret data in this research. A yarning circle is a recognised and validated Indigenous research In addition to the research team, the partners in this research are three communities of Aboriginal and Torres Strait Islander women. The communities in this research will include intact communities of Aboriginal and Torres Strait Islander women who use digital technologies as a regular form of communication within the community.

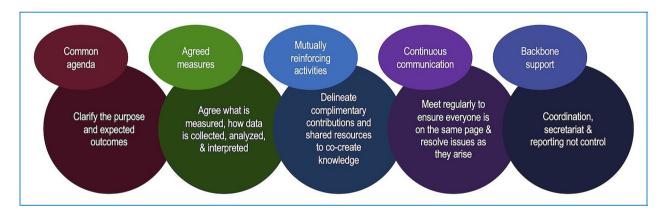


Figure 1. Collective impact - five success elements.

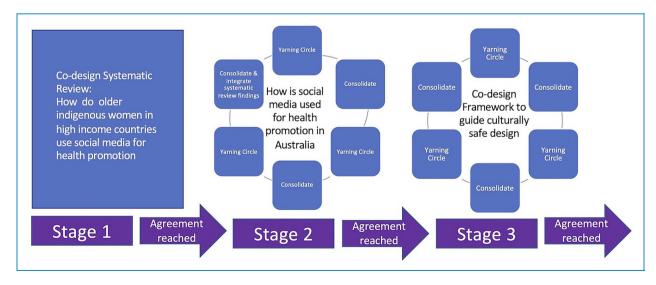


Figure 2. Delineate how social media is used and develop a framework.

Two communities (An Aboriginal and Torres Strait Islander business women's network and a community of Aboriginal and Torres Strait Islander who form an ecosystem of entrepreneurial women committed to helping each other succeed have pre-committed to participate in this research. Community leaders have expressed dismay associated with the impact of misinformation poor digital literacy on Aboriginal and Torres Strait Islander people. Each of these communities has asserted an interest in using their collective impact to influence health and wellbeing for Aboriginal and Torres Strait Islander people. The research communities include Aboriginal and Torres Strait women from urban, rural and regional Australia. A third similar community will be recruited. Participants will be community members who range from middle age to older adults who do not consider themselves to be 'digital natives'.

Participant recruitment and consent

All aspects of recruitment will be co-designed with the APG. Once we have an agreement on how to provide information and achieve consent in their community the APG chair will provide information about the research to members of her community and invite women, who express interest in the research and who are Aboriginal or Torres Strait Islanders to learn more about the project.

The initial information about the research project may be provided via phone, email, website or through social media depending on the needs and habits of the community. Women who express interest in participating will be provided a detailed Participant Information Sheet, that includes a description of the project i.e. who can participate; background information; how the findings will be used; what is required for participation; potential risks and benefits of participation. The names and contact details of the lead researchers will also be included on the participant information sheet, as well as information about the ethics approval for this project. After reading this information sheet and speaking with the APG chair to answer questions and to ensure she is fully informed about this project, the community member will be asked to sign a consent to participate form. Potential participants are also encouraged to contact the lead researcher if they want more information about the project. This project uses a transparent, co-designed research approach, thus the detailed protocol will be made available for any participants who express interest.

Participation in the research is 100% voluntary and participation is anticipated to be interesting and desirable for community members. At each stage of the project, participants will be asked if they wish to continue their participation in the next stage and they are encouraged to make that decision freely without any consequence for opting out at any point. The staged nature of the research allows for participant replacement at any point without impacting the overall integrity of the project.

An additional component of this research will include a pilot test of the co-designed health promotion program which will be pilot-tested with an online survey. A social media survey (n = 150) will elicit the views of Aboriginal and Torres Strait Islander people about the three programs including what did they like/not like. The survey will be anonymous and participants will self-declare their willingness to participate by clicking proceed button, after reading a brief description of the survey. Participants are free to abandon the survey at any point.

Study design

Part 1: Co-identify and co-develop a framework crystalising co-produced knowledge

A *co-designed Systematic review* will identify the strengths and gaps in the literature about how older Indigenous women in high-income countries use social media. We will refine the research question and define search terms through collaborative discussions with Aboriginal and Torres Strait Islander co-researchers. Collaboration early will enable us to create a 'common agenda', a critical success factor within the collective impact approach. It will also set the tone for privileging Aboriginal and Torres Strait Islander perspectives and ensure we address relevant research needs. We will pre-register the systematic review on PROSPERO and will be guided in our reporting by the Preferred Reporting Items for Systematic review and Meta-Analysis (PRISMA) Protocols 2015.^{46,47}

In the second stage, as illustrated in Stage 2 of Figure 2 – a series of yarning circles will identify how older Aboriginal and Torres Strait Islander, women use and could use social media to inform and influence the health of their communities. We will solicit information about the types of social media used and for what purpose by asking broad, openended questions, such as: 'What digital technologies are you currently using?' Follow-up questions will drill down on each of the currently used technologies, for example, 'What do you use - Facebook, etc - for?' 'Do you use the emojis to respond to posts; which ones do you mostly use, who do you share posts, with and when?'. The specific highlevel questions will be agreed with the APG chairwomen before the first yarning circle. Consistent with yarning circle methodology the discussions will be fluid and the chair women will have the autonomy to flexibly respond and intervene with the participants in her community. After each session the data will be consolidated and presented back as a starter for the next circle. The data from across the three groups will be consolidated, presented to the APG chairs and subsequently to each of the individual communities for reflection and discussion. Iterations will continue until a consensus is reached.

In stage 3 we will focus on developing and refining a framework that crystalises the co-produced knowledge that has emerged. The first framework draft will be created by consolidating and synthesising data from stages 1–2 using thematic analysis with the APG chairwomen. Next, a series of iterative yarning circles and revisions will refine the framework, which includes what the group believes works and does not work for health promotion in Aboriginal and Torres Strait Islander communities. We will then use the framework to inform the design of three health promotion programs (Case studies) in Part 2 of this project.

Part 2: Test and refine the framework using three case studies linked to existing co-design work with Aboriginal and Torres Strait Islander communities

In stage 4, we will co-design, co-implement and co-evaluate three social media health promotion programs, as illustrated in Figure 3. The first two social media health promotion programs will inform community members about the availability and value of participating in: (1) breast screening and (2) atrial fibrillation (AF) screening programs. A third program will inform community members about precision medicine, how it works, and why it may be relevant for Aboriginal and Torres Strait Islander people. This information is essential because precision medicine is becoming the gold standard for diagnosing and treating many cancers and rare diseases but is typically not well understood by the general public.

The co-researchers in each community will review and evaluate a range of previously designed social media health promotion campaign materials, using the framework created in Part 1 as criteria for evaluation. After each circle, the information will be consolidated and presented back as a starter for the next circle for refinement until an agreement is reached on a draft design. This design will be pilot tested with an online survey. A social media survey (n = 150) will elicit the views of a cross section of Aboriginal and Torres Strait Islander people including men non-binary people and other age cohorts about the three programs, including what did they like/not like. The specific questions for the survey will be generated by the participants, consolidated across the three groups, presented back to the participants to discuss and refine and agreed with the APG chairs. The survey will include questions such as: 'Which aspects of the social media campaign do you think are most/least effective? Why? 'Which aspects of the social media campaign did you like/dislike? Why? Which aspects of the campaign should we change? Why?' The survey will also include an anonymous baseline knowledge test using nonidentifying data where people self-declare eligibility. The knowledge questions will include items such as 'what was the key message of the social media campaign from your perspective?' And 'Were there any other message that you noticed? If yes what were those messages? The data from this survey will be consolidated around the themes of what is working and not working in the draft programs. Yarning circles will incorporate the data from the surveys and refine the design of the campaign.

In stage 5, we will co-design the social media campaign evaluation. Depending on the social media platform chosen for the campaign, the metrics may include impressions, clicks, likes, shares for posts. 'Agreed Measurement' is a crucial success factor in the collective impact approach and will ensure transparency and consensus about what is measured and how data is collected, stored, analysed and used. Thus, the evaluation criteria (which social media metrics and qualitative data should be collected) will be generated by the participants and consolidated across the three groups, presented back to the participants to discuss and refine. The final questions will be agreed with the APG chairs. The data will be collected throughout the implementation and analysed upon program completion. In stage 5b, summaries of consolidated data, analysis and

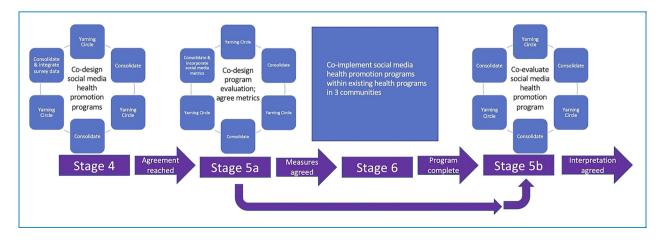


Figure 3. Test and refine the framework using three case studies.

interpretation will be presented to the participants to reflect upon and refine. Iterative discussions will continue until consensuses is reached. In stage 6, each of the three social media health promotion programs will be co-implemented in each community.

Analysis

The yarning sessions will be recorded and transcribed. The transcriptions will be analysed using thematic analysis. At each stage, the themes will be presented back to the participants for review and revision until consensus is reached. Content data derived from the online surveys will also be analysed using thematic analysis. Descriptive statistics will be used to summarise the data collected through social media analytics which will also be presented to the participants for review and incorporation into their yarning circle. We will use QSR Nvivo1248 to assist with data management and analysis. Findings from each step of the project will be presented to the APG's within each community on an ongoing basis, as part of the governance meetings. The APG's will review all manuscripts before publication, ensuring cultural safety and Aboriginal and Torres Strait Islander leadership and self-determination throughout the life of this project.

Discussion

This paper presents a mixed-methods translational research protocol that will privilege the cultural expertise of older Aboriginal and Torres Strait Islander women to create and test a framework to guide culturally safe and effective digital health program development. This is the first research project that will prioritised older Aboriginal and Torres Strait Islander women's perspectives about health technology. Prioritising their perspectives is important because Aboriginal and Torres Strait Islander women are influential and provide strong cultural leadership in their communities.24,31,32,40,41 The women's status within their communities positions them to bring a novel and valuable perspective about the health needs and priorities for their communities. Likewise, they are in a position to envisage how women could practically use technology to influence health. Moreover, privileging women's perspective and deep cultural expertise ensures the research will be relevant and benefit Aboriginal and Torres Strait Islander communities.

The active participation and commitment intrinsic in the collective impact approach promotes community capacity building and transferability by integrating local culture and local health organisations' practices into every aspect of the program design. Collaboration, capacity building and transferability are essential for research with Aboriginal and Torres Strait Islander people to ensure cultural safety, efficacy and sustainability which has often been lacking in health research with Aboriginal and Torres Strait Islanders.

Limitations

Participants in this research will participate via online meetings, which require access to a device and an internet connection. Previous research has found that even in remote communities mobile phone and social media use is high in Aboriginal and Torres Strait Islander communities.^{21,22} However, the requirement for participants to have internet access may bias the sample towards people who have easier access or are more comfortable with technology. Similarly, because participants in this research will be volunteers, the sample may be biased towards people who are attracted to the research topic, potentially limiting the generalisability to Aboriginal and Torres Strait Islander people who have no interest in health technology.

Knowledge to action

A key output is a framework that details how social media health promotion works and does not work in Aboriginal and Torres Strait Islander communities. Developers of digital health promotion campaigns can use this framework to ensure their programs are safe and effective for Aboriginal and Torres Strait Islander people.

The framework will include recommendations that were found to be relevant across the three research communities and will also highlight any specific aspects that need to be tailored to individual communities. Using this framework will limit the burden on Aboriginal and Torres Strait Islander people by consulting only when specific local contextual issues need to be addressed by developers.

The findings will be described in lay terms in written and video formats and provided to participants, partners and community members. These lay formats will make health science assessable, exciting and usable by non-scientists. And will ensure the project provides immediate benefit to Aboriginal and Torres Strait Islander community members. We will present the findings from this research to the state and federal government to advocate for policy change to ensure that digital health programs, including public health promotion campaigns in Australia, are inclusive, culturally safe and effective for Aboriginal and Torres Strait Islander people.

Conclusions

Health information is increasingly provided digitally. Likewise, the Australian government has prioritised research that uses technology to enable people to manage their health and promote better health outcomes. It is therefore a matter of ethical urgency that these technologies are made safe and effective for all Australians. The framework created and tested through this research will provide a path for greater inclusion and safety for Aboriginal and Torres Strait Islander people to access digital health information. **Acknowledgements:** The authors would like to thank the Poche Centre and Centre for Global Indigenous Futures at Macquarie University for their support of this research.

Conflict of interest: The authors have no conflicts of interest to declare.

Contributorship: Conception and design of the study – CH, MW, KG; Cultural Advice – BR, BC, CV; Governance – CH, BC, KG; Drafting the manuscript – CH, KG; Review and approval of the manuscript – all authors.

Ethical approval: This protocol has received ethics approval on 1 December 2021 # 1862/21. The research will be conducted in keeping with the National Health and Medical Research Council's Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities.

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References

- 1. WHO. Atlas of eHealth country profiles 2015: The use of eHealth in support of universal health coverage.
- Australian Digital Health A. Australia's national digital health strategy: framework for action. 2018. https://doi.org/APO-182341.
- 3. Australian Digital Health A. *Australia's national digital health strategy*. Canberra, Australia: Australian Digital Health Agency, 2017.
- 4. AIHW. Aboriginal and Torres Strait Islander health performance framework 2020 summary report. Camberra: Australian Institute of Health and Welfare, 2020.
- Reilly RE, Doyle J, Bretherton D, et al. Identifying psychosocial mediators of health amongst indigenous Australians for the heart health project. *Ethn Health* 2008; 13: 351–373.
- Sherwood J and Mohamed J. Racism a social determinant of indigenous health: yarning about cultural safety and cultural competence strategies to improve indigenous health. In: Frawley J, Russell G and Sherwood J (eds) *Cultural competence and the higher education sector: Australian perspectives, policies and practice*. Singapore: Springer Singapore, 2020, pp.159–174.
- Nolan-Isles D, Macniven R, Hunter K, et al. Enablers and barriers to accessing healthcare services for aboriginal people in New south wales, Australia. *Int J Environ Res Public Health* 2021; 18: 3014. DOI: 10.3390/ijerph18063014

- Vallesi S, Wood L, Dimer L, et al. "In their own voice"-incorporating underlying social determinants into Aboriginal health promotion programs. *Int J Environ Res Public Health* 2018; 15: 1514.
- Thurber KA, Colonna E, Jones R, et al. Prevalence of everyday discrimination and relation with wellbeing among Aboriginal and Torres Strait Islander adults in Australia. *Int J Environ Res Public Health* 2021; 18: 6577. DOI: 10.3390/ ijerph18126577
- Marmot M. Social determinants and the health of indigenous Australians. *Med J Aust* 2011; 194: 512–513
- Carlson B and Frazer R. The politics of (Dis) trust in indigenous help-seeking. In: Maddison S and Nakata S (eds) *Questioning indigenous-settler relations: interdisciplinary perspectives.* Singapore, Singapore: Springer Singapore Pte. Limited, 2019. DOI: 10.1007/978-981-13-9205-4_6
- Irving M, Gwynne K, Angell B, et al. Client perspectives on an aboriginal community led oral health service in rural Australia. *Aust J Rural Health* 2017; 25: 163–168
- Rheault H, Coyer F and Bonner A. Time to listen: chronic disease yarning with Aboriginal and Torres Strait Islander peoples living in remote Australia. *Collegian* 2021; 28: 10–17
- 14. Australian Institute of Health Welfare. *Cultural safety in health care for indigenous Australians: monitoring framework.* Canberra: AIHW, 2021.
- 15. Taylor K and Guerin P. *Health care and indigenous Australians: cultural safety in practice.* Third edition. London: Red Globe Press, 2019.
- AIHW. Australia's health 2020 data insights. Sydney, Australia: Australian Institute of Health and Welfare, 2020.
- Salmon M, Doery K, Dance P, et al. Defining the indefinable: descriptors of aboriginal and Torres Strait islander Peoples' cultures and their links to health and wellbeing. Canberra, Australia: ANU National Centre for Epidemiology and Population Health (NCEPH), 2018.
- Williamson L, Dent P and Bowman N. Culture is Key: towards cultural determinants-driven health policy – final report. Melbourne: Lowitja Institute, 2020.
- Burgess CP, Johnston FH, Berry HL, et al. Healthy country, healthy people: the relationship between indigenous health status and "caring for country". *Med J Aust* 2009; 190: 567–572
- Priest N, Thompson L, Mackean T, et al. 'Yarning up with Koori kids' – hearing the voices of Australian urban indigenous children about their health and well-being. *Ethn Health* 2017; 22: 631–647.
- Taylor AJ. Information communication technologies and new indigenous mobilities? Insights from remote northern territory communities. J Rural Community Dev 2012; 7: 59–73.
- Rice ES, Haynes E, Royce P, et al. Social media and digital technology use among indigenous young people in Australia: a literature review. *Int J Equity Health* 2016; 15: 81.
- 23. Carlson B and Dreher T. Introduction: indigenous innovation in social media. *Med Int Aust* 2018; 169: 16–20.
- Sweet MA. Social media: new links for indigenous health. *Med J Aust* 2013; 199: 18.
- Povey J, Mills PPJR, Dingwall KM, et al. Acceptability of mental health apps for Aboriginal and Torres Strait Islander Australians: a qualitative study. *J Med Internet Res* 2016; 18: 65.

- Hefler M, Kerrigan V, Freeman B, et al. Using facebook to reduce smoking among Australian Aboriginal and Torres Strait Islander people: a participatory grounded action study. *BMC Public Health* 2019; 19: 615–615.
- Hefler M, Kerrigan V, Grunseit A, et al. Facebook-based social marketing to reduce smoking in Australia's first nations communities: an analysis of reach, shares, and likes. *J Med Internet Res* 2020; 22: e16927.
- Hefler M, Kerrigan V, Henryks J, et al. Social media and health information sharing among Australian indigenous people. *Health Promot Int* 2019; 34: 706–715.
- Carlson B, Frazer R and Farrelly T. "That makes all the difference": aboriginal and Torres Strait Islander health-seeking on social media. *Health Promot J Austr* 2021; 32: 523–531. DOI: 10.1002/hpja.366.
- McPhail-Bell K, Appo N, Haymes A, et al. Deadly choices empowering indigenous Australians through social networking sites. *Health Promot Int* 2018; 33: 770–780.
- Warburton J and McLaughlin D. Passing on Our culture: how older Australians from diverse cultural backgrounds contribute to civil society. *J Cross Cult Gerontol* 2007; 22: 47–60.
- Warburton J and Chambers B. Older indigenous Australians: their integral role in culture and community. *Australas J Aging* 2007; 26: 5
- Busija L, Cinelli R, Toombs MR, et al. The role of elders in the wellbeing of a contemporary Australian indigenous community. *Gerontologist* 2020; 60: 513–524.
- Eysenbach G and Kohler C. What is the prevalence of health-related searches on the world wide Web? Qualitative and quantitative analysis of search engine queries on the internet. AMIA Annu Symp Proc 2003; 2003: 225–229.
- Du H, Yang J, King RB, et al. COVID-19 increases online searches for emotional and health-related terms. *Appl Psychol Health Well-Being* 2020; 12: 1039–1053.
- Rovetta A and Bhagavathula AS. Global infodemiology of COVID-19: analysis of google Web searches and Instagram hashtags. *J Med Internet Res* 2020; 22: e20673.
- Tsao S-F, Chen H, Tisseverasinghe T, et al. What social media told us in the time of COVID-19: a scoping review. *Lancet Digit Health* 2021; 3: e175–e194.

- Yigitcanlar T, Kankanamge N, Preston A, et al. How can social media analytics assist authorities in pandemic-related policy decisions? Insights from Australian states and territories. *Health Inf Sci Syst* 2020; 8: 37.
- Walker T, Palermo C and Klassen K. Considering the impact of social media on contemporary improvement of Australian Aboriginal health: scoping review. *JMIR Public Health Surveill* 2019; 5: e11573.
- Sweet M, Geia L, Dudgeon P, et al. #IHMayDay: tweeting for empowerment and social and emotional wellbeing. *Australas Psychiatry* 2015; 23: 636–640.
- Sweet M, Geia L, Dudgeon P, et al. Outlining a model of social journalism for health. *Aust Journal Rev* 2017; 39: 91–106.
- 42. Gwynne K. Applying collective impact to improve health services for Aboriginal people in rural and remote communities. Doctor of Philosophy PhD, University of Sydney, Faculty of Health Sciences, 2017.
- Gwynne K and Cairnduff A. Applying collective impact to wicked problems in Aboriginal health. *Metrop Univ* 2017; 28: 115–130. DOI: 10.18060/21740
- Bessarab D and Ng'andu B. Yarning about yarning as a legitimate method in indigenous research. *Int J Crit Indig Stud* 2010; 3: 37–50.
- 45. Walker M, Fredericks B, Mills K, et al. "Yarning" as a method for community-based health research with indigenous women: the indigenous women's wellness research program. *Health Care Women Int* 2014; 35: 1216–1226.
- Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; 6: e1000097.
- Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *PLoS Med* 2009; 6: e1000100–e1000100.
- 48. Tane MP, Hefler M and Thomas DP. An evaluation of the 'Yaka ENGarali'' tackling indigenous smoking program in East Arnhem Land: Yol engu people and their connection to engarali'. *Health Promot J Austr* 2018; 29: 10–17.