

Understanding Intimate Health in Public Spaces: A Study Protocol

Victoria Egli, Callie Vandewiele, Hanna Price, Caitlyn MacIntyre, Sarah Bickerton, Nina Duggan, Seline McNamee, Emmy Rakete, Alana Cavadino

Submitted to: JMIR Research Protocols on: August 11, 2024

Disclaimer: © **The authors. All rights reserved.** This is a privileged document currently under peer-review/community review. Authors have provided JMIR Publications with an exclusive license to publish this preprint on it's website for review purposes only. While the final peer-reviewed paper may be licensed under a CC BY license on publication, at this stage authors and publisher expressively prohibit redistribution of this draft paper other than for review purposes.

Table of Contents

Original Manuscript	5
Supplementary Files	
Figures	
Figure 1	
Figure 2	18
Figure 3	

Understanding Intimate Health in Public Spaces: A Study Protocol

Victoria Egli¹ PhD; Callie Vandewiele² PhD; Hanna Price³; Caitlyn MacIntyre²; Sarah Bickerton⁴ PhD; Nina Duggan¹; Seline McNamee⁵; Emmy Rakete⁵ PhD; Alana Cavadino⁶ PhD

Corresponding Author:

Victoria Egli PhD
The University of Waikato
Hillcrest Road, Hillcrest,
Hamilton
NZ.

Abstract

Background: Social media has become an important tool facilitating communication and connection in a post-pandemic landscape. This context has prompted an increase in the sharing of information and disinformation about general health, and provides an opportunity to seek information about and support for intimate health with the added assurance of maintaining a degree of anonymity in a socially taboo context.

Objective: The aim of this study is to better understand how women in Aotearoa New Zealand use social media to access sexual and reproductive health information and support. Engagement with stakeholders and community groups will be undertaken throughout the study to analyse the findings therein, and present solutions to identified issues.

Methods: This study uses a mixed-methods approach, involving the collection of qualitative and quantitative data through an anonymous survey on the Qualtrics Survey Software platform. Recruitment will occur through advertising on University social media accounts, and physical posters in various locations nationwide, prioritising often-underrepresented groups. This study will also present the preliminary results to stakeholders, prioritising whakawhanaungatanga and manaakitanga in the co-designing of future research aims. Subsequent analysis of all the above data forms will be performed, with dissemination of results in academic, participant, and stakeholder circles.

Results: Ethical approval to conduct this study was granted by the University ethical review board on June 23rd, 2023 and an amendment to change survey questions and expand recruitment was submitted June 5th, 2024. Data collection will occur until June 2025 with stakeholder engagement occurring throughout.

Conclusions: None

(JMIR Preprints 11/08/2024:65288)

DOI: https://doi.org/10.2196/preprints.65288

Preprint Settings

- 1) Would you like to publish your submitted manuscript as preprint?
- **✓** Please make my preprint PDF available to anyone at any time (recommended).

Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users. Only make the preprint title and abstract visible.

No, I do not wish to publish my submitted manuscript as a preprint.

- 2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?
- ✓ Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).

Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain v

¹The University of Waikato Hamilton NZ

²the University of Auckland Department of Anthropology Faculty of Arts Te Kura Tangata Auckland NZ

³Middlemore Hospital Te Whtu Ora Auckland NZ

⁴The University of Auckland Public Policy Institute Faculty of Arts Te Kura Tangata Auckland NZ

⁵The University of Auckland School of Social Sciences The Faculty of Arts Te Kura Tangata Auckland NZ

⁶The University of Auckland Epidemiology and Biostatistics Faculty of Medical and Health Sciences Auckland NZ

Original Manuscript

Understanding Intimate Health in Public Spaces: A Study Protocol

Egli, V, BN, MIPH, PhD*1 Vandewiele, C, PhD, 2 Price, H, BN Hons, 3 MacIntyre, C, BA Hons, 2 Bickerton, S, 4 Duggan, N, 1, McNamee, S, 5, Rakete, E, 5., Cavadino, PhD, A, 6

- 1. Te Huataki Waiora, The School of Health, The University of Waikato, New Zealand
- 2. Department of Anthropology, Faculty of Arts Te Kura Tangata, the University of Auckland, New Zealand
- 3. Middlemore Hospital, Te Whatu Ora, New Zealand
- 4. Public Policy Institute, Faculty of Arts Te Kura Tangata, The University of Auckland New Zealand
- 5. School of Social Sciences, The Faculty of Arts Te Kura Tangata, The University of Auckland, New Zealand
- 6. Epidemiology and Biostatistics, Faculty of Medical and Health Sciences, the University of Auckland

Abstract

Background: Social media has become an important tool facilitating communication and connection in a post-pandemic landscape. This context has prompted an increase in the sharing of information and disinformation about general health, and provides an opportunity to seek information about and support for intimate health with the added assurance of maintaining a degree of anonymity in a socially taboo context.

Objectives: The aim of this study is to better understand how women in Aotearoa New Zealand use social media to access sexual and reproductive health information and support. Engagement with stakeholders and community groups will be undertaken throughout the study to analyse the findings therein, and present solutions to identified issues.

Methods: This study uses a mixed-methods approach, involving the collection of qualitative and quantitative data through an anonymous survey on the Qualtrics Survey Software platform. Recruitment will occur through advertising on University social media accounts, and physical posters in various locations nationwide, prioritising often-underrepresented groups. This study will also present the preliminary results to stakeholders, prioritising whakawhanaungatanga and manaakitanga in the co-designing of future research aims. Subsequent analysis of all the above data forms will be performed, with dissemination of results in academic, participant, and stakeholder circles.

Results: Ethical approval to conduct this study was granted by the University ethical review board on June 23rd, 2023 and an amendment to change survey questions and expand recruitment was submitted June 5th, 2024. Data collection will occur until June 2025 with stakeholder engagement occurring throughout.

Keywords: sexual and reproductive health; social media; information dissemination

Introduction

During the Covid-19 pandemic social media peaked as a major tool for communicating health information and connecting people to each other during a time of physical distancing; it was widely

^{*}denotes corresponding author victoria.egli@waikato.ac.nz JMIR Research Protocols [IF 1.7]

used by public health professionals and conspiracy theorists alike [1]. Since the beginning of the Covid-19 pandemic, the use of social media for obtaining health information and support on all kinds of health-related topics has increased [2]. The use of social media to convey information and provide support in relation to socially taboo topics, specifically sexual and reproductive health, will be further investigated in this study, titled: Understanding Intimate Health in Public Spaces. We will focus on the experiences of women living Aotearoa New Zealand and their use of social media for sexual and reproductive health information and support. We define social media as any online environment that builds relationships and facilitates connection as well as the sharing of information and lived experiences of those who use it.

Sexual health is a state of complete physical, emotional, spiritual, mental and social wellbeing regarding sexuality, sexual orientation, sexual expression and gender identity. It also encompasses the ability of a person to have safe and pleasurable sexual experiences. Reproductive health extends this definition and focuses on a complete state of wellbeing in relation to the body's reproductive system and processes. Reproductive autonomy is a core feature of this definition, in that people have autonomy over whether, when, and by what means to have a child [3]. The achievement of optimal sexual and reproductive health is dependent on environments that affirm, promote and respect health for all individuals regardless of their sex assigned at birth or their gender. This includes environments that allow individuals timely access to comprehensive, high-quality and unbiased information [3] and where individuals are free from coercion and discrimination.

The COVID-19 pandemic accentuated the crucial role of social media in information dissemination. Social media can be an effective communication tool in times of crisis, as the need to quickly disseminate information is particularly pressing [4]. Equally, the interactive nature of social media allows individuals to seek support from others. Social media provides opportunity for connection, identity formation and a sense of group-belonging [5,6]. Online communities on social media provide options for individuals in relation to sexual and reproductive health information and support [7] — topics that are often shrouded in embarrassment and shame [8].

Despite appearing on the world stage to be socially progressive in many areas [9], Aotearoa New Zealand has a sexually conservative culture [10,11]. This makes seeking sexual and reproductive health information and support difficult for many. Fear of being judged, feeling shy, embarrassed, or ashamed, not knowing how to access it, and concerns about confidentiality are reported as reasons for unmet needs in sexual and reproductive healthcare service provision in Aotearoa New Zealand [12]. Adolescents and young adults appear to be the demographic most negatively impacted [12,13]. For Māori, stigma and negative societal attitudes towards sexual health intersect with the systemic racism inherent in Aotearoa New Zealand's health system [14,15]. This combines to negatively impact the way sexual and reproductive health information and support is accessed, as well as the quality of formal healthcare services provided [12,16]. As stigma intersects with other access barriers such as cost, transport, location, and availability, it is unsurprising then that people living in Aotearoa New Zealand seeking this information and support are turning away from traditional health care and towards social media.

In Aotearoa New Zealand, people who are Māori or Pasifika, have a disability, are overweight, or identify as lesbian, gay, bisexual, transgender, queer or questioning, intersexual, asexual, two-spirited, takatapui, or another marginalised identity are more likely to have negative, hostile, and stigmatising interactions with healthcare services [17-20]. Moreover, women from these vulnerable populations are more likely to face disparity and inequalities due to multiple levels of existing social injustice [21].

Women's sexual and reproductive health in Aotearoa New Zealand is of particular relevance due to the high incidence of sexually transmitted infections (STIs) in comparison to other Western countries [10,11]. National STI rates in Australia, the US, and the UK are lower than regional STI rates in Aotearoa New Zealand [10]. Women in sexual relationships with male partners older than themselves may be particularly at risk [11]. Other intimate health concerns include the long-term

mental and physical consequences of untreated STIs such as infertility and ectopic pregnancy [12,22], and the incidence of cervical cancer, which is often not adequately screened for in Aotearoa New Zealand [23].

For this study, we have chosen to define women as those who were assigned female at birth, and/or anyone who has ever self-identified, or currently self-identifies as a woman. Upon consultation with extended networks, we acknowledge this inclusive definition will not be favoured by everyone [24]. Defining gender and sexuality is an active space, recognising that these concepts are ever-evolving, and descriptions can and do change over time. Grounded in the underlying philosophical paradigm of intersectional feminism [25], this study will allow the researchers to understand women in Aotearoa New Zealand's experiences within health systems where they may encounter feelings of embarrassment, shame, and stigma, and their utilisation of social media for sexual and reproductive health information and support.

Methods

This study aims to:

- 1) better understand the relationship between social media and women's sexual and reproductive health in Aotearoa New Zealand, and
- 2) meaningfully engage with stakeholders and community groups to interpret the findings and propose solutions to identified problems.

This cross-sectional, mixed methods research will be conducted over 24 months in three stages. Stage 1: Data collection. Using an anonymous online survey on the Qualtrics Survey Software platform both quantitative and qualitative questions will be available for participants to complete. These combine a mixture of closed and open-ended text response options. No questions are mandatory. The full survey is (below/appendix). At the end of the survey participants will be directed to an optional, separate link, not connected to their survey responses where they are able to provide contact details if they wish to receive a summary of the findings. Meaningful and appropriate research results dissemination is a priority for this project and the research team have experience using innovative and creative approaches to research results dissemination [26,27]. The research team includes a graphic designer who will be involved developing the summary to go to participants. Participant recruitment will occur through social media posts from the University (details removed for peer review) social media platforms, see Figure 1. below. Funding has been allocated to push recruitment to specific population groups often underrepresented in online research, and those who are also the focus of this research. Physical advertisements of our research will be displayed on local community notice boards, coffee shops, gyms, libraries, local Marae, beauty salons, toilets, and supermarkets nationwide. The physical advertisement is shown in Figure 2. Below.

Figure 1. Social media participant recruitment advertisement.



Figure 2. Physical participant recruitment advertisement.



<u>Stage 2: Presentation of findings to stakeholders.</u> The research team will undertake preliminary data analysis and present these findings to community stakeholders and engage them for assistance with interpretation and making of meaning. Author 1 and Author 3 have existing relationships with Māori

healthcare providers, Hāpai Te Hauora, Sexual Wellbeing Aotearoa, and The Cancer Society New Zealand, who will all be warmly invited to participate meaningfully. Additional stakeholders may also be invited through the research team and stakeholder networks. It is likely that this stage 2 will include a mix of in-person stakeholder hui (workshops), kanohi ki te kanohi (face to face) meetings individually and in small groups. Whakawhanaungatanga (building relationships) and manaakitanga (kindness and respect for others, emphasising responsibility and reciprocity) will be prioritised throughout, using a flexible approach to best meet the needs, availability and preferences of the stakeholders. The aim of the stakeholder engagement activities is to get feedback on the findings of Stage 1 and to facilitate the co-design of future research priorities. It is anticipated that one of the research approaches that stakeholders will want to co-design with us using the results of this survey as a foundation for further investigation are in depth interviews. This is described in stage 3.

Stage 3: Interview Guide and Pilot Interviews. Based on the results of the survey and the stakeholders' engagement, a research approach and interview guide will be developed and piloted with approximately five to eight participants. The authors acknowledge this will require an amendment to existing ethics approval. The aim of stage 3 is not to reach qualitative data saturation, but to confirm a research approach and interview guide for an in depth qualitive study in the future. Interviews will be offered in English and Te Reo Māori. Interviews will be audio recorded and transcribed verbatim. Interviews conducted in Te Reo Māori will have both forward and backwards translation into English by a certified University (details removed for peer review) approved translator. Interview participants will be sent copies of their interview transcript and have 2 weeks to edit or add to the written version of the transcript. Each interview participant will receive a \$50 supermarket voucher as koha (gift) as a token of acknowledgement to their contribution to the research.

Data analysis: The multiple forms of data obtained in stages 1-3, including: qualitative survey results, the interpretation and meaning developed with stakeholders, the interview guide, and the pilot interview transcripts will be analysed together using a collective team approach to reflective thematic analysis [28]. The quantitative survey results will be analysed using descriptive statistics.

Results dissemination: The findings will be disseminated in academic conference presentation, peer-reviewed journal articles, summary reports to participants, detailed reports to stakeholders and through the University (details removed for peer review) social media accounts.

Results

Ethical approval for the online survey was granted from (details removed for peer review) on 28/06/2023 for three years, with amendments approved on 01/07/2024 #(details removed for peer review).

The timeline of our research is presented in Figure 3. below.

Figure 3. Timeline

	Timeline				
	2023	2024		2025	
Activity and Outcomes	Oct - Dec	Jan - June	July - Dec	Jan - June	July - Dec
Stage 1					
AHREC amendment					
Extend survey recruitment					
Stage 2					
Stakeholder engagement and					
wha kawhana unga tanga			ongoing throughout		
Analayse preliminary results					
Hui/workshops with stakeholders					post submination of funding applications a cationatory hu with all stationations and matricipations
Submit papers 1, 2 and 3 for					
publication					
Stage 3					
Co-design study protocol and					
external funding applications					
Apply for Marsden (\$360,000)					
Apply for MBIE Endeavour fund					
(\$1 Million)					
Apply for HRC Project (\$1.2					
million)					
Apply for Google Award for					
Inclusion (\$94,000)					

Discussion

The Understanding Intimate Health in Public Places project aims to better understand the relationship between social media and women's sexual and reproductive health in Aotearoa New Zealand. A strength of the approach we have described is the meaningful involvement of stakeholders in the interpretation and meaning making of the survey findings and input into the anticipated next phase of the research, in depth interviews. This study takes a multidisciplinary approach bringing together researchers from a variety of disciplines including public health, biostatistics, nursing, public policy, as well as anthropology and the social sciences. The aim of doing so is to better understand from diverse perspectives how and if social media impacts some of the most intimate aspects of the health of marginalised groups in Aotearoa New Zealand, namely the sexual and reproductive health of women.

Acknowledgements

The authors wish the thank the (details removed for peer review) Transdisciplinary Ideation fund for financial support of this research. The authors also wish to thank staff from Hāpai Te Hauora, Sexual Wellbeing Aotearoa, and The Cancer Society New Zealand for their informal feedback into the planning of this project and collegial support of the research team.

Conflicts of Interest

None declared.

Abbreviations

LGBTTQIA+: people who identify as lesbian, gay, bisexual, transgender, Takatāpui, queer or questioning, intersexual, asexual, or another marginalised identity.

Multimedia Appendix 1

References

- 1. Cinelli M, Quattrociocchi W, Galeazzi A, Valensise CM, Brugnoli E, Schmidt AL, Zola P, Zollo F, Scala, A. The COVID-19 social media infodemic. Sci Rep-UK. 2020;10(1):1-10. doi:10.1038/s41598-73510-5
- 2. Tsao SF, Chen H, Tisseverasinghe T, Yang Y, Li L, Butt ZA. What social media told us in the time of COVID-19: a scoping review. Lancet Digit Health. 2021;3(3):e175-e194. doi:10.1016/S2589-7500(20)30315-0
- 3. Starrs AM, Ezeh AC, Barker G, Basu A, Bertrand JT, Blum, R, Coll-Seck AM, Grover A, Laski L, Roa M. Accelerate progress—sexual and reproductive health and rights for all: report of the Guttmacher-Lancet Commission. Lancet. 2018;391(10140):2642-2692. doi:10.1016/S0140-6736(18)30293-9
- 4. Venegas-Vera AV, Colbert GB, Lerma EV. Positive and negative impact of social media in the COVID-19 era. Rev Cardiovasc Med. 2020;21(4):561-564. doi:10.31083/j.rcm.2020.04.195
- 5. Clark JL, Algoe SB, Green MC. Social network sites and well-being: The role of social connection. Curr Dir Psychol Sci. 2018;27(1):32-37. doi:10.1177/0963721417730833
- 6. Marlowe JM, Bartley A, Collins F. Digital belongings: The intersections of social cohesion, connectivity and digital media. Ethnicities. 2017;17(1), 85-102. doi:10.1177/1468796816654174
- Giorgio MM, Kantor LM, Levine DS, Arons W. Using chat and text technologies to answer sexual and reproductive health questions: Planned Parenthood pilot study. J Med Internet Res. 2013;15(9):e203. doi:10.2196/jmir.2619
- 8. Waling A, Farrugia A, Fraser S. Embarrassment, shame, and reassurance: Emotion and young people's access to online sexual health information. Sex Res Soc Policy. 2023;20(1):45-57. doi:10.1007/s13178-021-00668-6
- "We will buy them back and we will destroy them" PM Jacinda Ardern on gun control in New Zealand. The Late Show with Stephen Colbert YouTube page. May 25, 2022. URL: https://www.youtube.com/watch?v=qai8LdcY9LQ [accessed 2024-07-18]
- Braun V. "She'll be right"? National identity explanations for poor sexual health statistics in Aotearoa/New Zealand. Soc Sci Med. 2008;67(11):1817-1825. doi:10.1016/j.socscimed.2008.09.022
- 11. Terry G, Braun V, Farvid P. Structural impediments to sexual health in

- New Zealand: Key informant perspectives. Sex Res Soc Pol. 2012;9(4):317-326. doi:10.1007/s13178-012-0089-y
- 12. Rose SB, Garrett SM, McKinlay EM, Morgan SJ, Bell S. 'Be nice to us, we're still learning': an online survey of young people in Hawkes Bay, New Zealand, about unmet need for sexual health care and improving access to services. Sex Health. 2021;18(5):394-404. doi:10.1071/SH21092
- 13. Denison HJ, Bromhead C, Grainger R, Dennison EM, Jutel, A. Barriers to sexually transmitted infection testing in New Zealand: a qualitative study. Aust NZ J Publ Heal. 2017;41(4):432-437. doi:10.1111/1753-6405.12680
- 14. Came-Friar H, McCreanor T, Manson L, Nuku K. Upholding Te Tiriti, ending institutional racism and Crown inaction on health equity. New Zeal Med J. 2019;132(1492):62-66. PMID:30921312
- 15. Cormack D, Stanley J, Harris R. Multiple forms of discrimination and relationships with health and wellbeing: findings from national cross-sectional surveys in Aotearoa/New Zealand. Int J Equity Health. 2018;17(26):1-15. doi:10.1186/s12939-018-0735-y
- 16. Tipene J, Green A. He Pūkenga Kōrero: Rangatahi and sexually transmitted infections in the Waikato. 2017. https://tewhariki.org.nz/assets/He-Pukenga-Korero-Final-Report-31-Aug-2017.pdf [accessed July 16, 2024].
- 17. Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. PloS One. 2013;8(8):e70855. doi:10.1371/journal.pone.0070855
- 18. Fredriksen-Goldsen KI, Kim HJ, Barkan SE, Muraco A, Hoy-Ellis CP. Health disparities among lesbian, gay, and bisexual older adults: Results from a population-based study. Am J Public Health. 2013;103(10):1802-1809. PMID:23763391
- 19. Harris R, Tobias M, Jeffreys M, Waldegrave K, Karlsen S, Nazroo J. Racism and health: The relationship between experience of racial discrimination and health in New Zealand. Soc Sci Med. 2006;63(6):1428-1441. PMID:16740349
- 20. Puhl RM, King KM. Weight discrimination and bullying. Best Pract Res Cl En. 2013;27(2):117-127. PMID:23731874
- 21. Williams DR, Rucker TD. Understanding and addressing racial disparities in health care. Health Care Financ R. 2000;21(4):75-90. PMID:11481746
- 22. Price M J, Ades AE, Soldan K, Welton NJ, Macleod J, Simms I, DeAngelis D, Turner KME, Horner PJ. The natural history of chlamydia trachomatis infection in women: A multiparameter evidence synthesis. Health Technol Assess. 2016;20(22):1-250. PMID:27007215
- 23. Hider P, Dempster-Rivett K, Williman J, Dempster-Rivett M, Sadler L, McLeod M, Miller, A, Sykes, P. A review of cervical cancer occurrences in New Zealand 2008–2012. New Zeal Med J. 2018;131(1472):53-63. PMID:29565936
- 24. Arayasirikul S, Turner C, Trujillo D, Sicro SL, Scheer S, McFarland W, Wilson EC. A global cautionary tale: discrimination and violence against trans women worsen despite investments in public resources and improvements in health insurance access and utilization of health care. Int J Equity Health. 2022;21(1):1-11. doi:10.1186/s12939-022-01632-5

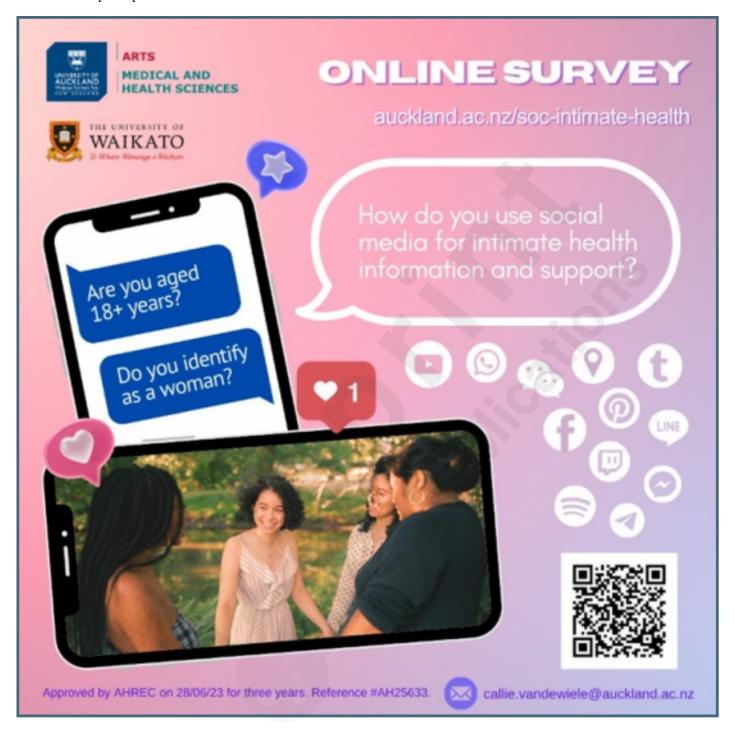
25. Carastathis A. The concept of intersectionality in feminist theory. Philos Compass. 2014;9(5):304-314. doi:10.1111/phc3.12129

- 26. Egli V, Carroll P, Donnellan N, Mackay L, Anderson B, Smith M. Disseminating research results to kids: Practical tips from the Neighbourhoods for Active Kids study. Kōtuitui: NZ J Soc Sci Online. 2019;14(2):257-275. doi:10.1080/1177083X.2019.1621909
- 27. Williams L, Tavares T, Egli V, Moeke-Maxwell T, Gott, M. Vivian, the graphic novel: using arts based knowledge translation to explore gender and palliative care. Mortality. 2023;28(3):383-394. doi:10.1080/13576275.2021.1929898
- 28. Clarke V, Braun V. Thematic Analysis: A Practical Guide. Thousand Oaks, CA: SAGE Publications Ltd; 2021. ISBN: 9781473953246

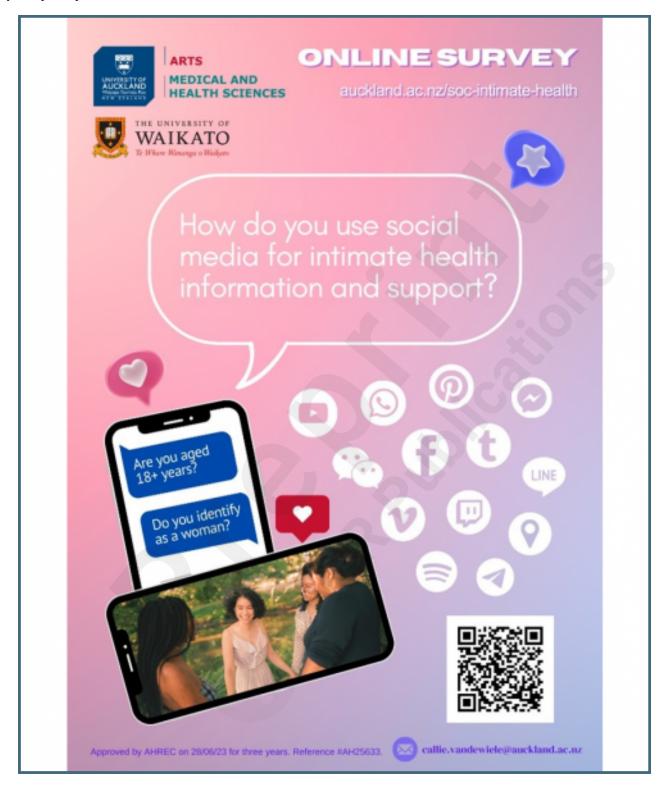
Supplementary Files

Figures

Social media participant recruitment advertisement.



Physical participant recruitment advertisement.



Timeline.

	Timeline					
	2023	2024		2025		
Activity and Outcomes	Oct - Dec	Jan - June	July - Dec	Jan - June	July - Dec	
Stage 1						
AHREC amendment						
Extend survey recruitment						
Stage 2						
Stakeholder engagement and whakawhanaungatanga			ongoing throughout			
Analayse preliminary results						
Hui/workshops with stakeholders					post submission of funding applications a celebratory had with all stakeholders and research partners	
Submit papers 1, 2 and 3 for						
publication						
Stage 3						
Co-design study protocol and external funding applications						
Apply for Marsden (\$360,000)						
Apply for MBIE Endeavour fund (\$1 Million)						
Apply for HRC Project (\$1.2 million)						
Apply for Google Award for Inclusion (\$94,000)						