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Wāhi Kōrero: The Development of an Online Story-Sharing Research Platform for Health Research

Christina Severinsen[1], **Mary Breheny**[1], **Angelique Reweti**[1], and **Felicity Ware**[2]

Abstract

Storytelling has the power to forge connections and foster empathy, providing insights into shared human experiences. In the digital age, online platforms offer opportunities to amplify historically underrepresented voices. This article introduces Wāhi Kōrero, a bespoke online story-sharing platform designed to collect stories from people whose experiences are often absent from health research. Wāhi Kōrero was developed through a collaborative approach between Indigenous and non-Indigenous researchers and web designers, prioritizing ethical considerations, cultural respect, and inclusivity. Wāhi Kōrero provides a safe and welcoming space for people to share their experiences, crafted in their own words, with minimal researcher involvement. Analyzing these stories can reveal the structural inequities that shape personal experiences with health professionals. The platform's transformative impact extends to power dynamics, political discourse, and knowledge production. Wāhi Kōrero works toward a collectively determined health research agenda, elevating the voices of health service users and validating their expertise in their own lives and health. Ultimately, Wāhi Kōrero exemplifies the changing landscape of online information access, presentation, and control, paving the way for a more equitable and inclusive approach to health research and practice.

Keywords

health seeking; healthcare; marginalized or vulnerable populations; methodology; qualitative; online research; storytelling; health services; Indigenous; access to healthcare

> Whenever we raise our voices collectively, change is inevitable.
>
> (Nii Armah Sowah, 1000 Voices Project)

Introduction

Storytelling has an inherent power to forge connections and communicate shared human experiences. It fosters empathy, allowing people to gain deeper insights into themselves and others (Stephens & Breheny, 2013). Gergen and Gergen (2006) describe narration as a powerful lever for human change, benefiting both tellers and listeners. As technology evolves, online platforms present unique opportunities to hear the stories of people historically excluded from health research. To harness this potential, we developed Wāhi Kōrero, a bespoke online story-sharing platform designed to amplify the accounts of people whose health experiences are often overlooked. Wāhi Kōrero enables both tellers and listeners to learn about others, addressing the need for more inclusive narrative data collection.

Guided by a critical public health perspective, Wāhi Kōrero focuses explicitly on individuals and groups whose experiences of unmet health needs have been underrepresented. To ensure authenticity and cultural responsiveness, we undertook a collaborative approach between Indigenous and non-Indigenous researchers and web designers. This collaboration facilitated the co-creation of a welcoming environment for open story-sharing, prioritizing ethical considerations, cultural respect, principles of empowerment, and inclusivity. This article reports on the design of Wāhi Kōrero, exploring how the platform has been used, the

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[1] School of Health Sciences, Massey University, Palmerston North, New Zealand
[2] Hāpai Te Hauora, Henderson, New Zealand

Corresponding Author:
Christina Severinsen, School of Health Sciences, Massey University, Private Bag 11222, Palmerston North 4442, New Zealand.
Email: c.a.severinsen@massey.ac.nz

stories shared, and the insights gained from its implementation and the implications for power dynamics, policy change, and knowledge production in health research.

Background

Online research methods offer promise for inclusive research, and different approaches provide specific benefits and limitations. Shifting qualitative health research online requires deliberate consideration of the assumptions, aims, and methods of data collection (Carter et al., 2021; Newman et al., 2021). This shift gained momentum during and after the COVID-19 pandemic as researchers adapted to continue their work amid social restrictions. Typically, familiar qualitative methods such as individual and focus group interviews and photo elicitation methods were transposed to online platforms using video conferencing and photograph-sharing tools (Newman et al., 2021). Initially, the online environment was viewed primarily as a solution to a pandemic-induced problem of access to participants. As such, online research tended to be compared to face-to-face data collection strategies to assess relative quality, suitability, or risk. For example, Davies et al. (2020) found that online-generated accounts tended to be shorter and include less contextual detail than face-to-face accounts. Other studies noted that online methods presented unique participant risks to privacy that need careful consideration (Carter et al., 2021; Davies et al., 2020; Newman et al., 2021). However, solely relying on these comparisons overlooks a crucial aspect: the potential for online qualitative health research to provide participants with a different kind of experience and to collect distinctly different data. This suggests the need to explore novel opportunities that online methods present for inclusive and innovative health research.

The distinct advantages of online research have been embraced by using naturally occurring social media data. Online forum posts, Instagram accounts, or Facebook communities are increasingly analyzed (Germain et al., 2018). While social media data occur naturally, these are not curated for research purposes, presenting both opportunities and challenges. It enables researchers to observe how people discuss health topics in their everyday online interactions. However, this approach limits researchers' ability to respond to health issues identified as important priorities for communities and to gather in-depth, purposeful responses. In addition, the use of social media data raises complex ethical considerations, particularly regarding whether the data are public or private and in maintaining informed consent (Germain et al., 2018). Consent may be sought from forum moderators or website owners rather than individual contributors, potentially compromising participant autonomy to consent to research. These limitations highlight the need for online research methods that can capture first-hand accounts while addressing ethical concerns and allowing more targeted, community-driven research. Such methods could better reflect the priorities and needs of the communities being studied, offering a middle ground between the naturalistic observations of social media and the structured approach of traditional qualitative research.

The potential of online research to enable participatory storytelling and amplify a diverse range of voices has been widely recognized (Horrell et al., 2015; Kent, 2016). Participants are empowered to view themselves as experts in their own health experiences in the context of living with structural disadvantage (West et al., 2022). This method is particularly suited to representing the nuances of cultural and ethnic differences in experiences of health and healthcare (McCall et al., 2021). By employing online narrative methods, researchers can access a range of perspectives, capturing the nuances of individuals' lived experiences more effectively than conventional qualitative methods. Projects like the 1000 Voices Project demonstrate how users can become active citizens rather than just users of technology (Clapton, 2010; Sunderland et al., 2015). Online platforms have proven particularly valuable in amplifying Indigenous experiences and generating qualitative data for research (Sunderland et al., 2015). Online storytelling may reveal common storylines across groups and encourage participation from people from diverse cultural backgrounds (Greenhalgh, 2013). The capacity to gather and analyze diverse narratives makes online storytelling a powerful tool for inclusive health research.

Digital storytelling, which captures personal stories on multimedia digital videos, offers innovative knowledge translation and can be empowering for participants (West et al., 2022). However, this approach also presents significant challenges. The intensive video production required can limit accessibility and require considerable resources from both participants and researchers. This resource-intensive process may inadvertently reinforce power dynamics between researchers and the communities they study, potentially excluding those with limited time or support for participation. Consequently, digital storytelling may be less suitable for people with chronic health conditions, mobility limitations, or significant caring responsibilities—groups whose voices are crucial in health research and policy discussions. Recognizing these limitations, researchers have turned to online storytelling platforms as a more inclusive alternative. These platforms offer a means of participation to those who are marginalized, ignored, disempowered, excluded, or silenced in public spaces (Sunderland et al., 2015). By reducing technical barriers and resource requirements, online storytelling platforms can facilitate broader participation.

Digital and online methods, including digital storytelling, social media research, and online surveys, offer means for narrative collection yet have constraints for inclusive, empowering participant engagement. Naturalistic approaches to storytelling, which allow narratives to emerge spontaneously, informally, and without structural constraints on what is considered important or legitimate (Sunderland et al., 2015), have proven effective in qualitative data collection (Greenhalgh, 2013). This embrace of spontaneity and informality in online storytelling not only generates more authentic and impactful qualitative data but also promotes more inclusive participation. Consequently, these naturalistic online narrative methods have the potential to contribute significantly to the development of more culturally relevant and effective public health interventions.

Hearing narratives from underrepresented people is imperative for creating public health interventions, services, and policies that aim to improve equitable outcomes. However, gathering these narratives can be challenging. Health is often viewed as a moral imperative, where people are made responsible for their own health outcomes based on their lifestyle choices rather than considering the social determinants of health (Brown, 2013; Warbrick et al., 2016). This leads people to conceal information to avoid judgment (Kent, 2016). Recognizing this gap between the need for diverse narratives and the barriers to sharing them, we developed the Wāhi Kōrero online story-sharing platform. This platform aims to provide an inclusive online space where people can safely share and read first-person accounts.

Wāhi Kōrero—Real Stories for Change

Wāhi Kōrero is a bespoke story-sharing platform (https://www.wahikorero.co.nz/) developed specifically for online qualitative research. It provides a space for people to share their personal accounts of health, recognizing that these stories not only reflect individual experiences but also reveal the impact of structural inequities on individual lives and population groups, uncovering systemic patterns of disparity (Breheny et al., 2021). The platform offers an open space for contributors to independently construct narratives in direct response to researcher-posed prompts. In developing the Wāhi Kōrero platform, we prioritized an ethical, culturally responsive, and collaborative approach to promote the inclusion of diverse narratives and perspectives related to health experiences. This design philosophy is reflected in the platform's asynchronous, self-directed process, which promotes radical participant empowerment within the knowledge-creation process. By allowing individuals to share their experiences without mediation, Wāhi Kōrero provides a transformative approach to qualitative health research.

Wāhi Kōrero offers an accessible space where people can respond to story prompts designed to encourage the sharing of often challenging health experiences. The use of prompts is critical to the platform's design; Wāhi Kōrero prompts allow us to collect data that capture the nuances of people's ordinary health encounters. This approach builds on people's willingness to disclose their personal experiences online to ensure their story is told. It also enables the research team to design prompts that explore inequities in service delivery. The prompts are brief and open-ended to avoid pre-determining the kinds of stories that might be shared. They are collaboratively developed by all members of the advisory group and research team, striking a balance between openness and conciseness whilst focusing on generating data about barriers and inequities faced in the health system. The goal of Wāhi Kōrero is to strategically amplify those who are least heard (boyd, 2009), acknowledging and addressing inherent biases by prioritizing the inclusion of individuals often silenced or overlooked in public discourse. Given the potential sensitivity of narratives elicited online, ethical considerations and safeguards were paramount throughout the Wāhi Kōrero design and development process. Wāhi Kōrero received ethical approval from the Massey University Human Ethics Committee (Application SOB 21/30). Care was taken to ensure the safety and well-being of those who share their stories on the platform, creating an environment of trust and respect where participants can authentically express their experiences without fear of judgment or misuse.

The Research Team and Approach

Indigenous and non-Indigenous researchers collaborated to create Wāhi Kōrero, embodying commitments to reciprocal knowledge exchange, decolonization efforts, and challenging existing power imbalances with academic research. In the context of Aotearoa New Zealand, this collaboration is grounded in Te Tiriti o Waitangi, the country's founding agreement, which was designed to enable British governance while safeguarding Māori sovereignty. Our partnership reflects power-sharing and equitable contributions to the design and implementation processes. To effectively bring together the strengths of two distinct worldviews and knowledge systems, we adopt a comprehensive approach epitomized by the Māori metaphor of "he awa whiria" (braided river) (Macfarlane et al., 2024). This framework acknowledges that addressing issues disproportionately affecting Indigenous peoples solely within Western knowledge systems is insufficient. Instead, we integrate mātauranga Māori, Indigenous knowledge derived from a reciprocal relationship between tāngata whenua (Indigenous people of Aotearoa) and the Aotearoa New Zealand environment.

As the two knowledge systems converge, they retain their distinctiveness, fostering a richer comprehension reflective of local realities. This approach not only enhances the overall research but also ensures that Māori researchers maintain the autonomy to employ Māori methodologies, preserve data sovereignty, and engage with the research in ways that benefit Māori communities.

Wāhi Kōrero is rooted in Māori cultural concepts. The name combines "wāhi," meaning location or place, with "kōrero," encompassing the act of telling, talking, or speaking (Williams, 1971, p. 142). We acknowledge that some people may be more inclined to contribute and have many avenues to assert their opinions and share their experiences. We intend to actively seek out the experiences of people who are missing or excluded in public discussions or may perceive their experiences as not worth sharing. To embody its inclusive ethos, Wāhi Kōrero's visual identity incorporates design elements inspired by te ao Māori, the Māori world. The branding images reflect the shapes and symbols of a wharenui, a Māori meetinghouse with significant cultural, linguistic, and community importance. By incorporating these architectural shapes and patterns, the site evokes a gathering place and a sense of community and safety, which aligns with Māori values and aspirations.

The Design and Development of Wāhi Kōrero

Conceptualization

The design and development of Wāhi Kōrero was a collaborative process involving various stakeholders. We established our kāhui rangahau, an expert advisory group that included representatives from various backgrounds and expertise, ensuring ethnic representation. Our kāhui rangahau includes medical professionals, Māori and Pacific leaders, maternal and child health experts, disability advocates, youth health and development experts, mental health and addiction leaders and service user advocates, and LGBTQIA+ health advocates. This group's involvement spans the entire research process, from securing funding to developing story prompts, engaging in ethical discussions, and discussing the evolving analysis. Through consensus decision-making, this group plays a pivotal role in co-designing each project, ensuring that Wāhi Kōrero reflects a wide range of perspectives and addresses the needs of diverse communities.

The design and development of Wāhi Kōrero involved a comprehensive process that integrated research objectives with professional branding and user experience considerations. During Stage 1, we collaborated with a creative agency to ensure that the platform's design aligned with our public health values while meeting high standards of sophistication and attractiveness. This approach was crucial for facilitating community engagement and building user confidence. The design process began with the development of a comprehensive design brief, which included branding elements and audience targeting. The platform's visual identity was carefully crafted to reflect its purpose and values. For instance, casual text styles were employed to emphasize the concept of kōrero, symbolizing the act of sharing and speaking up. The chosen font conveys a sense of importance and influence, symbolizing the significant impact that individual voices can have within the community.

To enhance engagement, we integrated the branded website with active social media channels. This strategy, combined with professional branding and design, was essential in establishing Wāhi Kōrero as a credible, inviting, and safe space for sharing health experiences and contributing to research. The investment in high-quality design ensures the platform's long-term usability and flexibility, allowing our team to adapt to various research topics and maintain project momentum in response to current health issues.

User Profiles and Journeys

Stage 2 of the Wāhi Kōrero platform development centered on the creation and application of user profiles to align the platform's structure and content with our research objectives. Collaborating with designers, we developed five distinct user profiles to capture the different types of potential contributors, particularly those whose voices are often absent from other forums. These profiles—the non-sharer, coaxed sharer, cautious sharer, immediate sharer, and external researcher or policymaker—served as personas of fictitious users with similar needs and motivations when engaging with the technology (Cabrero et al., 2016). By considering the values and needs associated with each profile, we tailored the platform to meet the perspectives and motivations of different users. The user profiles were instrumental in shaping the user journey within the platform. We mapped out the stages of awareness, consideration, motivation, and action for each profile, enabling us to anticipate the steps users might take as they progress toward sharing their stories. This analysis of user journeys informed the creation of a coherent and intuitive structure and design for the Wāhi Kōrero site, allowing us to identify key transitions and potential barriers to engagement. Ultimately, this approach ensures that the platform's information architecture and content strategy were optimized to encourage participation from a wide range of contributors, particularly those whose health experiences are often underrepresented in traditional research forums.

Wāhi Kōrero was designed to accommodate and encourage varying levels of user engagement, recognizing that people differ in their willingness to contribute. The platform's structure can foster a gradual increase in user participation, from passive reading to active contribution. By providing a space for immediate users to share their experiences spontaneously, Wāhi Kōrero simultaneously creates opportunities for more hesitant visitors to learn and gain comfort in sharing their own stories. This design strategy anticipates that users who initially only feel comfortable reading the stories of others may, over time, develop a sense of community and connection, ultimately building their willingness to contribute.

The implementation of this user engagement strategy involved careful technical and ethical considerations. The final stage focused on creating a functioning and well-supported website, which included cross-browser testing and research team training. Concurrently, we developed the site's Terms of Use and Privacy Policy in accordance with ethics approval, taking into consideration the requirements of the ethics research committee and the needs of the intended users. This overall approach ensures that Wāhi Kōrero not only encourages user engagement but also maintains high standards of functionality, usability, and ethical practice.

Promoting Accessible Participation

The platform incorporates various measures to create a secure and supportive environment for participants, with a thorough moderation process at its core. Each submitted story undergoes a careful review by a member of our research team, and identifying details of people, places, or health services are removed. This approach was carefully deliberated with the kāhui rangahau, balancing the desire for personal identification against the potential or unintended consequences for story submitters (see Berkhout, 2013). The moderation process extends beyond simple anonymization, considering the level of detail in the story to prevent identification through unique circumstances, a concern highlighted by Saunders et al. (2015) in online research contexts. This moderation process also enables the filtering of inappropriate, destructive, or inflammatory content, safeguarding against website misuse. By implementing these moderation practices, we ensure that Wāhi Kōrero remains a safe environment where people feel secure in sharing their health experiences while maintaining the integrity and constructive nature of the platform.

Wāhi Kōrero employs a comprehensive approach to participant protection and ethical data management, encompassing informed consent, privacy safeguards, and culturally responsive data collection. Participants provide explicit informed consent and permission to use their stories for research at the time of submission, ensuring awareness of both public accessibility and research use. This process is supported by a detailed Privacy Policy and Terms of Use, which outline user obligations, intellectual property rights, content monitoring and removal, disclaimers, liability, user-submitted content, and suspension and termination of site use. To enhance user safety and privacy, we have integrated a safe exit function on the site, similar to those used on websites related to sexual or family violence. This feature allows users to quickly leave the site if they become concerned about using the site. All participant data are stored on secure servers, accessible only to the research team, prioritizing confidentiality.

The platform's design includes optional demographic questions about ethnicity, gender, and age, which can be tailored to each project's specific needs. For Project 2, additional identifiers like tāngata whai kaha (disabled people) and tāngata whai ora (mental health and addiction service users) were included, further refining the platform's ability to capture diverse health experiences. The collection of ethnicity data enables the identification of Māori stories, facilitating analysis from a kaupapa Māori perspective. This approach supports tino rangatiratanga (self-determination) in developing tailored health system responses, with Māori researchers leading data analysis.

The Wāhi Kōrero platform prioritizes inclusivity and user support through a range of features that accommodate diverse needs and preferences. Central to this approach is the platform's multimodality, which enables participants to share their stories via text, video, and audio. By enabling different modes of communication, we enhance accessibility for people with various abilities and cater to different communication styles and preferences. To further improve accessibility and inclusivity, the website incorporates a translation feature that allows users to instantly translate the main text into te reo Māori (the Māori language) with a single click. This functionality enables te reo Māori speakers to access and navigate the site comfortably in their preferred language.

The accessibility of the Wāhi Kōrero platform has been rigorously evaluated. An independent, pan-disability organization conducted a comprehensive assessment to ensure compliance with the New Zealand Government Web Accessibility Standard 1.1, the Web Content Accessibility Guidelines 2.2, and Web Content Accessibility Mobile Guidelines. This review involved a comprehensive evaluation of the website's accessibility, including manual, visual, automated, and assistive technology checks. Following this review, changes were implemented to enhance the platform's accessibility, aiming to provide everyone with an equal opportunity to share their experiences. To further support users, the site incorporates a Help section, which provides links to available support services, and a Frequently Asked Questions section offering additional research details. These resources are made available to participants upon submitting their stories, ensuring they have access to necessary information and support throughout their engagement with the site.

Encouraging Participation

Wāhi Kōrero uses a multifaceted strategy for community engagement and research dissemination designed to maximize participation, impact, and accountability. At the outreach level, we have built partnerships with community groups and organizations to ensure that people learn about the research platform through trusted sources. This grassroots approach is complemented by our social media presence on Facebook, Instagram, and TikTok, which serve to build a following, promote the projects, increase website traffic, attract participants, and share example stories and research findings.

Our commitment to transparency and accessibility extends to our research dissemination practices. Wāhi Kōrero features a dedicated space for sharing research findings, publications, videos, blogs, and conference talks. This open dissemination not only increases accountability but also fosters community investment in the platform. Our commitment to producing academic publications, policy and practice reports, and accessible summaries amplifies the reach and impact of the research (see Severinsen et al., 2024a, 2024b).

Our Wāhi Kōrero engagement model is bidirectional. We create opportunities for individuals and groups to suggest story prompts, thereby shaping the direction of future projects. Our approach has facilitated new partnerships with external organizations, enabling the identification of emerging issues of interest. The platform is a valuable resource for policymakers, who can gain insights from the submitted stories and the researchers' analyses (see Clapham et al., 2024; Severinsen et al., 2023).

The Wāhi Kōrero site enables researchers to capture extensive narrative data, facilitating the analysis of patterns and trends. However, its suitability may vary depending on the research topic. Some topics might be particularly suitable for an anonymous platform and this kind of text or audio story completion. Previous research has found that even when researchers attempt to establish communities of practice for research online, participants may only wish to deliver their stories and not engage in reciprocal or ongoing research relationships (Horrell et al., 2015). For other topics or demographic groups, established relationships and connections may be vital to build research trust.

Wāhi Kōrero Story Prompts

To date, we have used Wāhi Kōrero to run two story prompts to understand unmet health need. In 2021, the inaugural Wāhi Kōrero project used the story prompt, "Kōrero I wish I could've had with the Well Child nurse." This prompt was informed by our previous research with young parents, which found that feelings of shame and fear often silenced them and prevented them from receiving support (Severinsen et al., 2024c; Ware et al., 2018).

The prompt invited people to share their stories of nondisclosure with their Well Child nurse (early years health visitor). It encouraged stories about what people wished they could have talked about with their baby's health nurse: What did they feel they could not say? What questions would they have liked to ask? (Severinsen et al., 2023). Launched in August 2021 and running for nine weeks, the prompt elicited 420 stories, varying in length from 15 to 1255 words (median 135 words). The participant demographics reflected a diverse range of voices: Those who provided demographic information were predominantly women, with an average age of 34. Of the 61% who indicated ethnicity, 19% identified as Māori, 3% as Pacific, 81% as NZ European Pākehā, and 6% as other ethnicities. This first project demonstrated Wāhi Kōrero's effectiveness in gathering diverse health narratives. The complete collection of submitted stories is publicly accessible on the website (https://wahikorero.co.nz/projects/korero-i-wish-i-couldve-had-with-the-wellchild-nurse/).

The second Wāhi Kōrero project, launched in April 2024, explored the issue of unmet primary healthcare needs through the prompt, "I felt too whakamā to go to the doctor." Whakamā, a te reo Māori word, encapsulates the complex concept of personal or collective feelings of embarrassment or shame. This four-month project, concluding in August 2024, gathered 414 stories. Of the 350 who supplied demographic details, the majority identified as female/wāhine (266), with smaller numbers of male/tāne (25) and gender diverse/takatāpui individuals (20). The project also captured data on LGBTQIA+ identity (60 participants) and age ranges, categorized as rangatahi/young person (24), pākeke/adult (284), and kaumātua/older person (27). Ethnic diversity was well-represented, with 119 participants identifying as Māori, 24 as Pacific Peoples, 233 as NZ European/Pākehā, and 30 as other ethnicities. The project also gathered valuable data on health-related identities, with 80 participants identifying as tāngata whaikaha (disabled person and their whānau) and 47 as tāngata whaiora (mental health and addiction service users). In line with Wāhi Kōrero's commitment to accessibility and transparency, all submitted stories can be viewed on the website: https://wahikorero.co.nz/projects/i-felt-too-whakama-to-go-to-the-doctor/.

Analysis of stories submitted to Wāhi Kōrero reveals demographic patterns and experiences of marginalization among participants. Across both projects, stories are submitted by people identifying as Māori and Pacific relative to population proportions (Statistics New Zealand, 2023), and submitters have been predominantly female. Project 1 primarily attracted responses from women in their 20s and 30s, consistent with the high rates of active participation of mothers in online communities (Germain et al., 2018). In contrast, Project 2 received submissions from a broader age range, including youth and older people. Figure 1 shows a screenshot of the stories from both Prompt 1 and Prompt 2. The stories from both projects frequently described experiences of multiple marginalization. Participants reported dismissive treatment based on factors such as youth, poverty, or ethnicity and perceived substandard healthcare due to stereotyping related to drug-seeking behavior, weight, or chronic health conditions.

> I am Māori, and I absolutely think about my ethnicity when I access health care, whether it is from the hospital or the doctor. I was recently diagnosed with ADHD, as an adult. I struggled most of my life with ADHD related symptoms and challenges. Every time I tried to access support for diagnosis through the public health system, it was often implied that I was seeking drugs … Why would that be suggested? … There is bias everywhere in health for Māori. (Project 2)

Some participants explicitly questioned whether their ethnicity influenced the quality of care they received. Evidence of the effectiveness of Wāhi Kōrero as a digital storytelling method is also demonstrated by the stories submitted. Across both prompts, participants submitted stories describing inappropriate healthcare or missed opportunities for care:

> The Plunket nurse seemed more interested in ensuring I met her markers of success than actually supporting us as a family. Her questions were loaded "And you are breastfeeding aren't you" "And you put baby to sleep on her back in her own bed don't you." If I wasn't doing these things she made me feel that I was a lesser mother, doing things wrong and missed an opportunity to engage in conversation to respectfully share how to safely co sleep if that was my preferred choice. It closed the conversation and did not set a foundation for a respectful reciprocal relationship. From there, I resented going to appointments and have now stopped taking her. (Project 1)

> For a long time, I was having a really rough time in my relationship—my husband was violent and angry with me and the kids. When I was at the GP for another reason, I finally got the courage to mention the domestic violence to her and how I was worried about his mental health. She just shrugged and told me to bring him in for an appointment. Who has ever been able to "bring in" an angry man with mental health problems? She made it sound so easy. People are constantly told to talk about these things and reach out for help. But it can make it worse if professionals don't actively help, or when they dismiss your concerns. I don't think people like this GP understand the chaos, danger and fear that happen in domestic violence situations. I gave up, and felt so embarrassed for bringing it up and shut down. I didn't speak to anyone else about it for a few more years. (Project 2)

The platform provided an avenue for participants to reflect on health experiences and feelings that they had been unable to express. For many, these health experiences had diminished their confidence that health services would be respectful and meet their physical and emotional needs for support (see Clapham et al., 2024; Severinsen et al., 2023). This pattern of responses suggests that Wāhi Kōrero is receiving stories from people with complex health needs and multiple disadvantages and those who may be otherwise unlikely to participate in health research.

Transforming Power Dynamics

Wāhi Kōrero represents a methodological innovation in health research, offering distinct advantages over traditional data collection approaches. Our platform facilitates the gathering of authentic health narratives that are often only shared within close social circles, thereby accessing experiences often hidden from public health debate. By using comparatively open data collection strategies, Wāhi Kōrero creates a safe space for sharing and fostering a collective understanding of experiences. In conventional interview methods, participants must explain themselves to make their experiences make sense to others, interpret their experiences in alignment with researcher expectations, and implicitly or explicitly deal with interviewer reactions (Stephens & Breheny, 2013). Even in open-ended interviews, where participants have some latitude to share expansive narratives, the researcher typically guides questioning and responses are often based on participants' expectations for what counts as a good story and a plausible account (Wong & Breheny, 2018). Wāhi Kōrero, however, allows for asynchronous, participant-driven narrative sharing with limited researcher involvement. This autonomy enables participants to determine the relevant details, context, and scope of their stories without fear of follow-up questions, suspicion, or judgment. As Sunderland et al. (2015) note, "giving participants a high degree of discretion enables them to determine how, when and why they share their stories" (p. 55). This methodological approach aligns with public health, Indigenous (e.g., Smith, 2012), feminist, and disability scholars and is critical in narrative research (Gubrium, 2009; Sunderland et al., 2015). By privileging participant autonomy and authentic voice, Wāhi Kōrero captures valuable tacit health knowledge within communities, offering insights that might otherwise remain inaccessible through traditional paradigms.

Tēnā koe. Thank you for sharing your story. All identifying details will be removed so your story will remain anonymous.

I FELT TOO WHAKAMĀ TO GO TO THE DOCTOR

I went to the GP about perimenopause. First question: Do you smoke? and then he prescribed antidepressants. "You think you've got menopause? And what makes you think you're in menopause?...

I FELT TOO WHAKAMĀ TO GO TO THE DOCTOR

Heaps of times I've gone to the docs sick and been asked if I'm a druggy or alcoholic. Like they think I'm just there to feed a drug addiction. I've...

I FELT TOO WHAKAMĀ TO GO TO THE DOCTOR

In my family, we've been taught to believe that you basically had to be dying before you'd even think about going to the doctors - there's a GP shortage, they're...

KŌRERO I WISH I COULD'VE HAD WITH THE WELLCHILD NURSE

I wish I could have been honest about terrible sleep - I lied and said sleep was okay, because I didn't want suggestions to sleep train. I also didn't mention...

KŌRERO I WISH I COULD'VE HAD WITH THE WELLCHILD NURSE

I am a first time Mama and although I had all the support from Whanau and friends I still opted to do well-child checks instead of just going to doctors...

KŌRERO I WISH I COULD'VE HAD WITH THE WELLCHILD NURSE

I wish that the post natal support that I received was for both my child and myself. I had regular check in for my child's health, but our decision to...

KŌRERO I WISH I COULD'VE HAD WITH THE WELLCHILD NURSE

I chose not to take part in the Plunket system with my third baby after my experience with my Well Child nurse after having my second baby. I had a...

KŌRERO I WISH I COULD'VE HAD WITH THE WELLCHILD NURSE

I wish my nurse showed up to the visits she booked with me instead of canceling a couple hours later.

KŌRERO I WISH I COULD'VE HAD WITH THE WELLCHILD NURSE

I wish my nurse could have identified the abuse in my relationship. Domestic violence, in my case - emotional and psychological abuse, seems to be avoided and ignored by professionals...

Figure 1. Screenshot of the stories from both Prompt 1 and Prompt 2.

Wāhi Kōrero promotes knowledge transfer and communication accessibility by prioritizing participant autonomy in narrative construction. As such, researcher assumptions exert less influence on the topics covered, and participants retain control over the focus and detail of their narratives. While online responses may be shorter and include less contextual detail than face-to-face interviews (Davies et al., 2020), this does not diminish the quality or value of the collected data (Carter et al., 2021). Instead, Wāhi Kōrero encourages authentic expression by enabling participants to curate their stories, deciding when, how, and why they share their experiences (Greenhalgh, 2013). Our platform affords participants the opportunity to reflect on the research prompt, respond at their own pace, and refine their responses before submitting. The process of storying can facilitate personal reflection and meaning-making around health experiences (McCall et al., 2021). This approach contributes to a gradual transformation of traditional hierarchies, where research on minority groups has been primarily conducted from dominant outsider lenses. Over time, this more participatory approach may incrementally shift agendas and research priorities to align more with communities' needs and perspectives (Cunsolo-Willox et al., 2012).

Wāhi Kōrero challenges conventional modes of story curation and interpretation. Stories are typically filtered through an analytic lens, with researchers exercising considerable authority over theme selection, extract choice, and narrative framing. In contrast, Wāhi Kōrero allows for the direct sharing of stories without the mediating influence of "expert opinion, interpretation, or analysis" (Sunderland et al., 2015). This approach lessens the influence of health researchers' inherent assumptions and values on the presentation and reception of the research (Sunderland et al., 2015, p.49), even as researchers retain analytic authority through subsequent reports and publications. Viewing the stories directly engenders a form of radical empowerment, potentially redistributing influence and power to individuals and communities. Consequently, Wāhi Kōrero has the capacity to reshape power dynamics inherent in health settings, offering a more democratic platform for the expression and dissemination of health experiences.

Secondly, Wāhi Kōrero enhances knowledge dissemination by making the stories available for all to read, creating a community where often-hidden experiences can be shared and acknowledged. This public sharing serves multiple purposes. It validates these experiences, potentially reducing feelings of personal shame or isolation. It facilitates conversations about the broader social factors underlying health inequities (Kent, 2016). This approach empowers community members to connect their personal experiences with systemic factors. The shared stories challenge dominant narratives that place blame on individuals for health outcomes and may empower people to advocate more effectively for themselves in healthcare settings. In addition, to ensure accessibility and transparency, participants and the public have access to easily understandable textual and video summaries of the research and academic papers, all available through the Wāhi Kōrero platform and social media.

Thirdly, the Wāhi Kōrero platform offers a unique advantage through its transparency of the evidence base to policymakers and end users. By allowing policymakers, practitioners, and other stakeholders to access both the submitted stories and the researchers' analysis, we have the potential to bridge the knowledge gap between those writing policy and those who are the target of policy (Kent, 2016). This transparency serves multiple purposes. It ensures that analytic findings accurately reflect participants' narratives, enhancing the credibility of the research. The public nature of the shared stories increases the likelihood that participants' voices play a pivotal role in shaping policy and driving practice changes. Evidence of this impact is already emerging; during data collection, several non-government organizations, health professionals, and government agencies reached out to discuss the project, findings, and future actions. Their desire to be involved in discussions illustrates how Wāhi Kōrero created a sense of collective responsibility to enact changes based on research findings. Wāhi Kōrero develops a new standard of transparency in research practice, redefining the relationship between researchers, participants, and end users of research findings.

Limitations and Future Considerations

One of the limitations of the Wāhi Kōrero platform is the potential for participants to write experiences that are powerful and meaningful to them but may not be directly linked to the prompt. This presents a challenge in incorporating these experiences into the research analysis, as they may not align with the specific research objectives or themes. However, we recognize that these divergent experiences may indicate the need for a safe space to share these stories and find catharsis. In such cases, developing new prompts or providing opportunities to explore additional issues could be beneficial in accommodating and acknowledging these narratives.

Although the platform is designed to create a safe space for telling personal stories, there is a risk that people with more institutional power will use the platform to undermine the prompt and discredit marginalized views. For example, while the first prompt was open, a Well Child nurse submitted a story that described some young mothers as unreliable and lazy and framed them as the problem to shift attention away from potential shortcomings in health services. Such accounts can undermine the safety and inclusivity of the online space for contributors. The moderation process can be used to screen and prevent the sharing of posts that perpetuate harmful narratives or derail the intended purpose of the projects. Alternatively, if these responses are infrequent, they can be treated as alternative stories, as their rarity suggests that they do not disrupt the purpose of the prompt or the safety of the platform. If the platform becomes a site of conflict and antagonism, this may dissuade those with marginalized identities from sharing their experiences.

Once the stories are approved onto the Wāhi Kōrero platform, anyone can see and read them. This is a deliberate decision to create a communal repository of stories of unmet health need. However, this openness also means that the researchers have no control over the reproduction of these stories by people outside the research team. The public health ethics and empowerment values that underpin the platform and the creation of the prompts and their subsequent analysis do not protect the stories from being used by and for other purposes, such as analysis that denigrates the story writers or seeks to attribute blame to individuals for their health experiences.

Finally, a limitation of any online research is digital exclusion. Not everyone has the same access to technology and the internet, and efforts should be made to bridge these gaps. For these reasons, Wāhi Kōrero was designed to support text entry as well as uploading audio or video files to increase accessibility. There is recognition in the literature that online data collection strategies might enable participation in health research for people with mobility limitations, chronic health conditions, or significant care responsibilities (Carter et al., 2021; Horrell et al., 2015). As such, online research may be more suited to some participant groups and some topics than others; these decisions should be based on consultation with experts and community advocates rather than a pre-emptive assessment of the inclusion possibilities of different groups (Carter et al., 2021). Mikulak et al. (2023) describe participation in online research as an opportunity to develop digital skills among people with learning disabilities and advocate for challenging the conditions that create barriers to participation. Considering the needs of diverse users when developing the Wāhi Kōrero platform was an important step in enhancing participation for people with disabilities. Continuing to address disparities in digital access is crucial to ensure that increasing the use of online research does not create new exclusions in access to health research (Carter et al., 2021).

Conclusion

The Wāhi Kōrero research platform upholds the principle that everyone has a story to tell. Some people assume their stories are worth hearing, and the voices of such people inundate research, while others are marginalized or silenced. This research upholds the relevance and value of everyone's stories. Wāhi Kōrero provides a place to come together, a place to speak and be heard. It creates an online community of people sharing common health issues and experiences. The design process was based on these values: recognizing different kinds of contributors, making careful use of language and imagery, and creating a safe space to share experiences. This contributed to creating a following, encouraging new ways to recruit marginalized voices, and engaging genuinely and respectfully in that space. Wāhi Kōrero holds transformative potential at multiple levels, extending beyond personal narratives to reshape health research systems and paradigms toward equity and inclusion. The knowledge generated through Wāhi Kōrero can reshape the health research landscape, addressing existing power imbalances in defining priorities and driving more inclusive and responsive approaches within health systems. Analyzing health stories is a way to identify the social and structural drivers of unmet health need that may be internalized as individual failings to achieve good health (Chaufan et al., 2015). Furthermore, Wāhi Kōrero story prompts arise from current challenges faced by whānau and communities. Engagement with communities allows the emergence of storyline prompts, and Wāhi Kōrero is a grassroots approach to informing policy. Wāhi Kōrero elevates the voices of health service users and their expertise in their own lives and health.

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C.S.: Conceptualization, methodology, formal analysis, investigation, writing—original draft, and funding acquisition. M.B.: Conceptualization, methodology, formal analysis, investigation, writing—review and editing, and funding acquisition. A.R.: Conceptualization, methodology, formal analysis, writing—review and editing, and funding acquisition. F.W.: Conceptualization, methodology, formal analysis, writing—review and editing, and funding acquisition.

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Ethical Statement

Ethical Approval

The project received ethical approval from the Massey University Human Ethics Committee (Application SOB 21/30).

ORCID iD

Christina Severinsen https://orcid.org/0000-0003-0451-6728

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