

## Improving breast cancer outcomes: Breast Cancer Journey Mapping Project

*Me aro koe ki te hā o Hineahuone. Ko Hineahuone te mana o ngā wāhine, nā te wāhine he whenua, nā te wāhine te whakapapa, nā te wāhine te oranga.*

*He wāhine he whenua kā ngāro te tangata.*

*We pay homage to Hineahuone the first women on earth. It is from Hineahuone we gain life, substance and future generations. Without women humankind will perish. We therefore acknowledge the importance of protecting women and their lives from Breast cancer.*

### About:

As part of Breast Cancer Foundation NZ's and Sweet Louise's commitment to improving outcomes for women with breast cancer, we have embarked on a new project to better understand women's experiences of breast cancer. Through this, we want to learn key themes, common issues and opportunities for improvements and change. We will share the findings with participants and everyone interested to ensure we can collectively improve outcomes.

### How:

We have engaged Deloitte's expert health and cultural researchers to facilitate small, interactive workshops designed to foster open, safe, and meaningful discussions. The workshops will be held in-person in Christchurch, Auckland and Northland over two-three hours. There may be an option to join online. Koha will be provided and participants are welcome to bring a support person if they wish. Our teams will be available to support participants afterwards.

Please see below how we will ensure cultural safety and best practice. All personal information will be deleted and used for the purpose of recruitment only, and all outputs will be generalised and non-identifiable.

### Who:

We are seeking women who have been diagnosed with breast cancer in Aotearoa between 2020 & 2024, with a particular focus on the following groups:

- Wāhine Māori
- Pacific women
- Women who were diagnosed after finding a lump or other symptom (rather than routine screening)
- Women diagnosed under 40 years old

These groupings, along with the locations selected, prioritise where evidence shows higher incidences of breast cancer, later diagnosis and worst outcomes.

**When:** Workshops held over February and March.

**If you would like to participate, please fill out the survey here -**

[www.surveymonkey.com/Journey-Survey-Feb2025](https://www.surveymonkey.com/Journey-Survey-Feb2025)

**Please share with anyone you think would be interested.**

Thank you for your support of this important kaupapa. Please reach out to [adelec@bcf.org.nz](mailto:adelec@bcf.org.nz) if you have any further questions or would like to be receive the findings.

**Our commitment to culturally and psychologically safe care for people:**

We acknowledge the utmost importance of keeping people safe throughout this project and have designed an approach to ensure this. Their experiences are taonga and will be treated as such throughout the project.

To ensure safety in recruiting participants in this kaupapa, we will recruit primarily through networks which patients are comfortable and familiar with, such as existing support groups, relationships to Breast Cancer Foundation, Sweet Louise and/or partner organisations, and via people and organisations already known to the patients. Alongside this we will also create a wider call for participants through social media that will screen people based on workshop eligibility criteria before asking any personal information relevant to the way we will assemble participant cohorts. We endeavor to kōrero with participants to understand their perspectives and experiences throughout their cancer journey.

To ensure participant safety during workshops, these will be conducted by experienced facilitators from Deloitte's Health Advisory Practice who are culturally competent and come from the communities they are supporting.

### **Recruiting and engaging Māori and Pacific participants**

When working with Māori, we understand the importance of Kaupapa Māori research methodology to gain optimal engagement and outcomes for Māori. The principles of kaupapa Māori are: Whanaungatanga, Manaakitanga, Aroha, Mahaki, Mana, Titiro, Whakarongo, Kōrero, Kia Tupato, He Kanohi Kitea. (Detail of each principle is outlined in the appendix.) This ensures the engagement approach meets the cultural needs of Māori<sup>1</sup>. We understand that not all wāhine Māori are the same and that they all have unique needs and tikanga that we must understand to better reach and help save more lives. We must also understand these unique needs before we kōrero with wāhine Māori to get their whakaaro on their breast cancer experiences that aligns with their needs.

Pacific peoples refers to the diverse cultures of Polynesia, Melanesia, and Micronesia. While each island community has its own unique characteristics, they share several core cultural values: family, collectivism, consensus, reciprocity, love, respect, and spirituality. In order to effectively engage with Tagata Pasifika, the use of Yavu principles (Foundations of Pacific Engagement)<sup>2</sup> ensures our engagement is meaningful, relevant and culturally grounded with Tagata Pasifika. This includes knowing who Pacific people are by taking the time to connect, recognising their contribution and teu le vā or nurturing the space and relationship.

In the recruitment stage, we would like to highlight one principle each for Māori and Pacific as an example:

- **Whakawhanaungatanga:** Kaupapa Māori research methods emphasises whakawhanaungatanga for recruitment. Examples of this is recruitment in communities where the researcher and/or research team has established trust through karakia, sharing kai and respecting tikanga. This brings established trust to the project and supports ethical engagement. Breast Cancer Foundation alongside Deloitte will leverage existing networks and relationships to arrange whakawhanaungatanga to give a background to the project, establish trust and explain the processes before inviting Māori participants. Note that for recruitment through Marae, a whakatau process will need to occur.
- **Teu le vā:** When working with Tagata Pasifika, nurturing the space and relationships or teu le vā is essential. This requires a bridge of trust to be built prior to recruiting to provide a positive platform for Tagata Pasifika to feel valued and engaged. Members of the Deloitte Pasifika Services team Pās Peau, alongside Breast Cancer Foundation and Sweet Louise, can meet with potential participants and their family to explain the purpose, process and reassure their safety so they feel respected, informed and confident in their involvement. Strong relationships with Tagata Pasifika begin with authentic engagements from the outset. By developing these connections, we can ensure meaningful participation and engagement, leading to richer stories that will enhance our understanding of Pacific peoples breast cancer journeys.

### **Kaupapa Māori wānanga/talanoa/workshops.**

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<sup>1</sup> Smith, L (2000) *Kaupapa Māori Research: Reclaiming indigenous voice and vision.*

<sup>2</sup> [mpp.govt.nz/assets/Resources/Yavu-Booklet.pdf](http://mpp.govt.nz/assets/Resources/Yavu-Booklet.pdf)

Once the recruitment has been completed all wānanga will be facilitated by Cynthia Otene and conducted in line with Kaupapa Māori methodologies, which will align with the cultural needs of wāhine. Cynthia is a Kaupapa Māori researcher who has experience and fluency in Te Reo Māori. Cynthia is a clinical diabetes podiatrist with over 20 years of experience providing clinical services to hauora Māori providers, Marae clinics and Iwi. Additionally, Cynthia is a doctoral research candidate who has recently completed her doctorate wānanga utilising Kaupapa Māori methodology; this included wānanga and whakatau on the marae.

Supporting Cynthia with Pacific engagements is Karine Moka, who brings over 12 years of experience in health and education for both Māori and Pacific communities. With broad experience in project management and workshop facilitation, Karine is committed to fostering positive change across the health sector and achieving equitable outcomes for Māori and Pacific peoples.

## **Appendix A: Kaupapa Māori Principles**

**Whanaungatanga** - building and maintaining relationships. The process of establishing meaningful, reciprocal and whānau-like relationships through cultural respect, connectedness, and engagement.

**Manaakitanga** - sharing, hosting and being generous. It supports collaborative research and evaluation and helps knowledge flow both ways between researcher/evaluator and participant. This could mean inclusions like kai and koha to ensure sacredness of tapu and noa.

**Aroha** - love and respect. Treating people with respect means allowing them control where to meet, on their own terms, and when to meet. Aroha in how information is collected - letting participants decide what is public or confidential and the ability to participate anonymously and withdraw where needed.

**Mahaki** - showing humility when sharing knowledge. Mahaki reminds us to share knowledge and experiences to understand each other better and to foster trust in the relationship.

**Mana** - power, dignity, and respect. Kaua e takahia te mana o te tangata “Do not trample on the mana or dignity of a person”. People are the experts on their own lives, including their experiences, needs and aspirations.

**Titiro, whakarongo, kōrero** - look, listen and then speak. It’s important to look and listen to develop understanding and find a place to speak from. Take time to understand people’s day-to-day realities, priorities, and aspirations to make questions relevant to the participant.

**Kia Tupato** - being cautious. Being culturally safe, staying safe might mean working with elders and others in the community who can guide your research and evaluation when needed and doing this in a respectful way.

**He kanohi kitea** - being a familiar face. Seek to be involved with communities and become familiar to them to build trust and communication.

## **Appendix B: Principles for Pacific Recruitment Strategy**

When recruiting and engaging Tagata Pasifika, we will be guided by these principles and considerations to ensure cultural safety.

**Teu le vā** - Nurturing the space between; essential to building trust and a positive platform for Tagata Pasifika to feel valued.

- Teu le vā is about establishing trust, and holding space for an introduction of the project, process and the people who will conduct Talanoa with each group.
- Once trust and a positive platform has been established, participants can then be invited to join workshops.

**Flexibility and Accessibility** - Making the Talanoa as accessible as possible

- Recruitment and Talanoa will be held in person where possible. These will be held in areas accessible to Pacific communities, such as community centres.
- In Talanoa, we hold space for people to speak freely and as long as they need. This requires flexibility in the timings of agenda set in introductory Talanoa and in the workshops.

**Pasifika networks** - Access to Pasifika providers and community organisations

- We will recruit through established networks and relationships with organisations and people who participants already know and are comfortable with.

**Reciprocity** - Ensuring knowledge gained from research will be used to benefit Tagata Pasifika

- When introducing the project and the processes, we will highlight how this project will benefit Tagata Pasifika and how we plan on giving back the synthesised insights about Tagata Pasifika's experiences.