

'I felt too whakamā to go to the doctor'—how feelings of shame stop people seeking health care

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Health services struggle to provide affordable and nondiscriminatory health care to <u>Māori</u>, <u>Pacific</u>, <u>disabled</u>, and <u>rainbow</u> whānau, according to the latest <u>NZ Health Survey</u>.

Nearly a quarter of Māori reported unmet <u>primary care</u> needs over the past year, signaling deep cracks in the system.

It is important that we understand these gaps in health care access and why health care remains out of reach for so many. Our earlier research suggests this is about more than cost and poor logistics.

To investigate the complex reasons behind unmet health care needs in Aotearoa New Zealand, we have launched a <u>new research initiative</u>, using the online platform Wāhi Kōrero to provide users with an anonymous space to share their experiences with the health system. Early results suggest systemic biases that prevent equitable access and stop some people from even seeking health care.

Examining barriers to health care

The project invites people to share their stories in response to the prompt "I felt too whakamā to go to the doctor."

Whakamā refers to a feeling of embarrassment or shame that can deter people from seeking necessary health care. The research explicitly seeks to uncover these health service experiences as a way to improve health outcomes and reduce persistent health inequities.

The experiences of those who do not seek care tend to be absent from conventional health and consumer experience surveys. Rather than focusing on times when care was insufficient, our research invites people



to anonymously share their stories of when care was not even sought.

This is a new approach to existing understandings of unmet need. Unlike health care service reviews, our research deliberately seeks the voices of people who forgo care.

The telling of unmet need

The stories already submitted to Wāhi Kōrero expose the complexity of unmet needs and the multiple barriers preventing equitable access to health care.

One participant shared, "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 stressed and underfunded."

Another recounted a <u>traumatic experience</u> disclosing <u>family violence</u> and being dismissed by their GP: "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."

A trans participant described their experience of misgendering: "When I called to make an appointment with the GP I tried to give them some info so they didn't misgender me. I told the lady on the phone my preferred name. She said that wasn't possible, I had to go by my 'real' name. So I didn't show up for the appointment."

The stories also shed light on the challenges people with invisible illnesses and neurodivergence face. One participant shared their struggle to receive an accurate diagnosis: "I've only just now received an ADHD diagnosis after years of being told I had <u>major depression</u>, including a three-day hospitalization at a psychiatric ward."



Empowering voices and driving change

In addition to contributing their own stories, participants and readers can access and learn from the experiences shared by others on the Wāhi Kōrero platform. This collective storytelling fosters a sense of community, reduces feelings of isolation and promotes understanding of the diverse challenges people seeking health care face.

By reading these stories, people can see that they are not alone in their struggles. It can be empowering to know others have faced similar challenges and that there is a growing movement to address these systemic issues.

Our research is more than data collecting. It is an opportunity to build understanding that makes health systems more responsive to people's realities. Behind the statistics are untold stories of people who feel whakamā and don't access medical help, worsening symptoms and preventable emergency department visits.

Our research aims to generate insights that will guide policy and practice, ultimately improving <u>health outcomes</u> and reducing persistent inequities.

We are seeking more participants to share their stories in response to the prompt "I felt too whakamā to go to the doctor." For more information, please visit our <u>Wāhi Kōrero site</u>.

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