

**INSIGHTS | EXPERIENCES OF HEALTH IN
AOTEAROA FROM A LIVED EXPERIENCE
AND WOMEN'S* PERSPECTIVE.**



**changing
minds.**

He mana tō te mātau ā-wheako
Our lived experience is our strength



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Research Insights: Experiences of Health in Aotearoa from a Lived Experience and Women's* Perspective.

Changing Minds was contracted by Manatū Hauora to gather community insights on the experiences of women* with Lived Experience of mental distress and/or addiction or substance use, to inform their Pae Ora | Healthy Futures Women's Health Strategy.

Between 2 March and 13 March 2023 we invited people from the Lived Experience community to share insights into this research. It was important to us to provide different opportunities to engage that aligned with the individual's availability, accessibility, and privacy needs. Four research vehicles were used: hui, community whiteboard, social media and direct kōrero, and online form.

From 76 individuals we received 368 unique qualitative data points (over 11,000 words) in addition to demographic data when individuals chose to provide this.

This feedback can be summarised into eight key themes:

- Believe Us.
- Culture and Community insights.
- Education and Awareness.
- Going Beyond Western / Medical Model Healthcare.
- Our Health.
- Person Centred and Humanistic Approaches.
- Prejudice, Self-Stigma and Discrimination.
- Service and System Improvements.



0.1 Notes on Definitions and Language.

Women’s health is a diverse issue, covering diverse people. Our approach to this research is gender inclusive, as we know that a woman’s* perspective isn’t limited to people who were assigned female at birth, or who currently identify as female.

Where “Women*”, “Women’s*”, or “Woman*” was used in the recruitment, advertisement and insights gathering stages of this research, this term is inclusive.

Likewise, “Lived Experience” is not a homogenous description of experiences of people with history of mental distress and/or addiction. Everyone’s experience is unique. Changing Minds welcomes anyone with experience of mental distress and/or addiction.

0.2 Shaping the Direction of Insights.

It can be difficult to shape our stories into pre-determined questions, which can feel exclusive or feel as if the value of our insights is diminished. For that reason, across all our modes of data collection we started with an open-ended prompt:

“This is an open space for you to share any insights you'd like about healthcare in Aotearoa through women's and Lived Experience perspectives”.*

Following this, we asked specific questions of the community, which were adapted from the question framework provided by Manatū Hauora. *Note: These were adapted as follows for the limitations on delivery modes (specifically for length and clarity).*

Table 1: Questions across research platforms

Hui	Form	Community Whiteboard	Social Media
How does your experiences as a woman* with Lived Experience impact your experience of healthcare?	How does your experiences as a woman* with Lived Experience impact your experience of healthcare?	How does your experiences as a woman* with lived experience impact your experience of healthcare?	What do you want people to know about health as a woman* with LE?
If you could design a health system, what would your top three priorities be?	If you could design a health system, what would your top three priorities be?	If you could design a health system, what would your top three priorities be?	If you could design the health system what are your top 3 priorities?
What makes health experiences feel	What makes health experiences feel	What makes health experiences feel	What makes health experiences feel



positive and supportive?	positive and supportive?	positive and supportive?	positive and supportive?
What could be done in future to improve your experiences?	What could be done in future to improve your experiences?	What could be done in future to improve your experiences?	What can be done better in future to improve your experience?

1. Data Collection

1.0 Advertisement and Promotion

Changing Minds promoted the opportunity to participate in this research across our online and community networks, between 2 March and 13 March 2023 (11 days).

Table 2: Research recruitment engagement

	Organic Reach	Engaged Uses	Shares	Total Clicks
Facebook	411	44	5	46
Instagram	73	8	5	N/A
Instagram Stories	285	17	0	N/A
LinkedIn	376	51	6	20
Website Pop up	241	5	N/A	5
Newsletter	123	62	3	8

1.1 Ways to Contribute Insights

To reach a broad range of participants, and to facilitate participation in a way that felt best for the individual, four options to participate were offered:

1. Community Whiteboard – a public whiteboard where individuals could add their own notes, or support the notes added by others.
2. Direct Kōrero - through social media, email, or individual face-to-face or phone korero. This includes feedback using the Instagram Stories ask a question feature.
3. Hui – a one-hour online hui limited to 10 participants.
4. Confidential form – it was important to us to offer a completely confidential means of contributing to this mahi. A short form was created for feedback.



Table 3: Unique Responses

Format	Unique responses
Community Whiteboard	11
Direct Kōrero	18
Hui	10
Confidential Form	37
Total	76

1.2 Recognition of Contribution

Changing Minds believes in acknowledging the time and energy the Lived Experience community gifts to our research. With budget available, we offered:

- For hui participants – a \$50 putea aroha for their one-hour kōrero contribution.
- All other participants were entered into a random draw for one of three wellbeing gift-boxes (valued at \$50 each).

All participants who provided contact details to Changing Minds will receive a copy of our final report to use and share within their own communities. This will also be made available to the wider Lived Experience community through our website.

1.3 Further Engagement Opportunities

While a small amount of information has been collected from people within the Deaf Community, Changing Minds has been asked by the community whether there is scope and funding to hold a separate hui with the Deaf Community. This proposal has been put to Manatū Hauora.



2. About our Participants

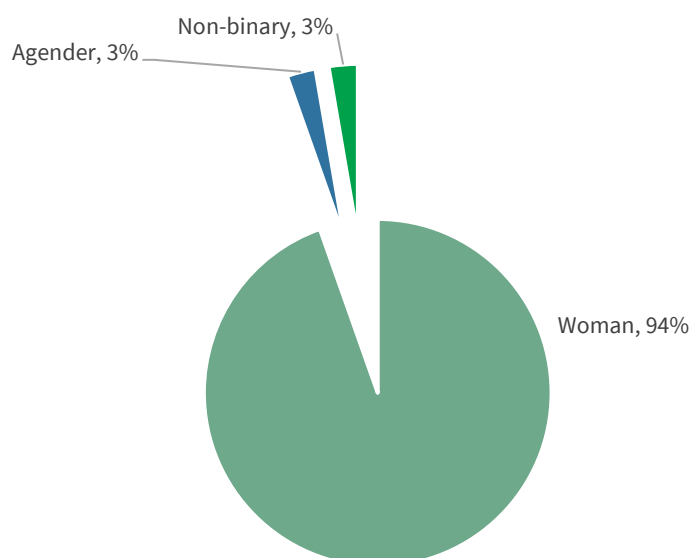
The criteria for participating in this research was that:

- The individual has Lived Experience of mental distress and/or addiction or substance use, AND
- The individual has experienced healthcare in Aotearoa New Zealand, AND
- The individual brings a women's* perspective (regardless of whether they are assigned female at birth, or *currently* identify as female).

Individuals were invited to contribute demographic information; however, this was non-compulsory.

Where demographic data was provided the following insights were collected:

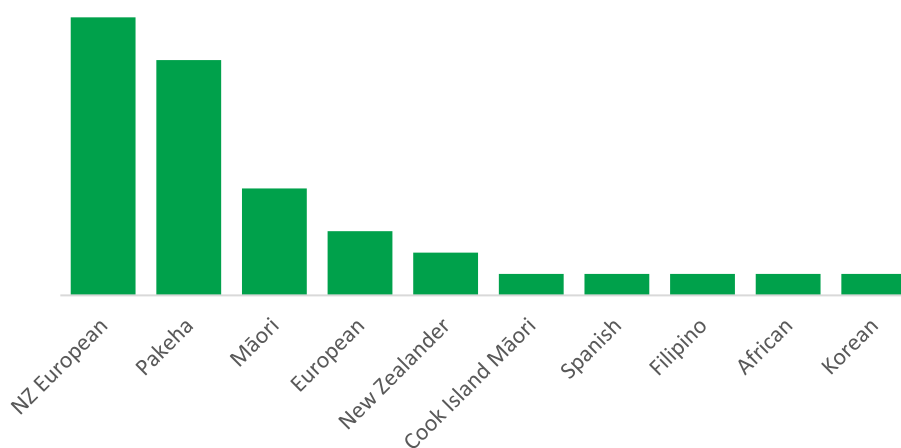
2.1 Gender Identity





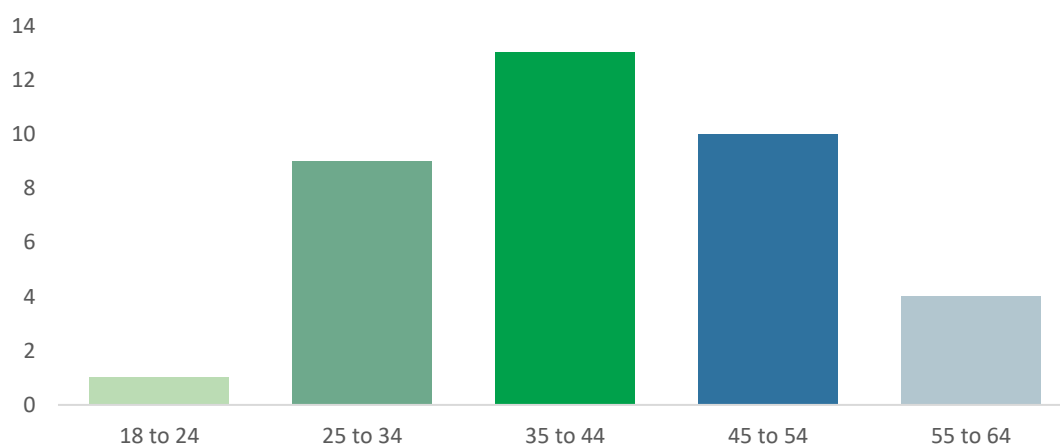
2.2 Ethnicity

What is your ethnicity (or ethnicities)?



2.3 Age

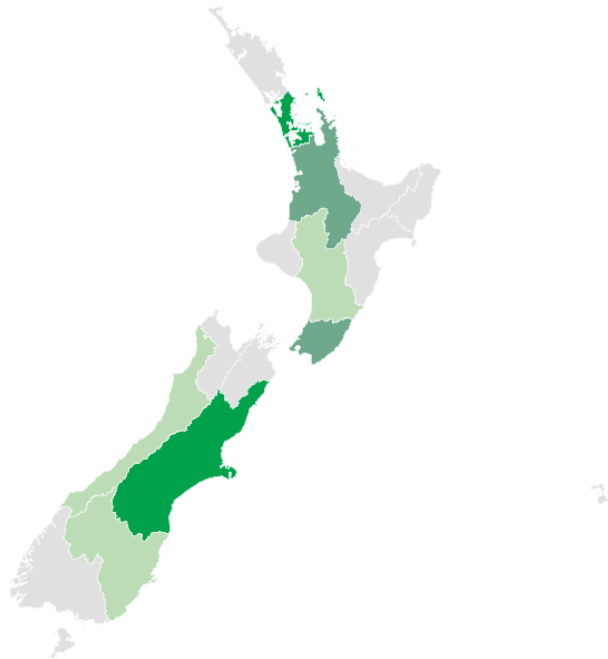
Age





2.4 Region

Which Region of Aotearoa New Zealand are you based in?



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- 35% of individuals are based in Auckland.
- 35% of individuals are based in Canterbury.
- 11% of individuals are based in Wellington.
- 11% of individuals are based in Otago.
- Remaining 8% of individuals are based in Manawatu/Whanganui, Waikato, or the West Coast.



3. Approach to Feedback

Changing Minds took feedback first approach to the coding of qualitative data. Data was anonymised before four reviewers undertook an initial review to generate emerging codes and themes. Where there were discrepancies between the codes these were resolved by the lead reviewer.

From 337 pieces of feedback, 61 codes were identified. 63 per cent of feedback items spoke to a single concept. 37 per cent spoke to two or more concepts, and 13 per cent spoke to three or more concepts.

These codes were then reviewed and collated into seven key overarching themes (as well as an additional ‘other’ theme).

Table 4: Themes and related codes

Believe Us	Diagnostic Overshadowing
	Feeling - Being Believed
	Feeling - Isolation
	Feeling - Listened To
	Feeling - Supported
	Normalisation
	Self-Advocacy
Culture and Community insights	Culture
	Deaf Community Insights
	Tamariki, Youth, Young People
Education and Awareness	Current & Best Practice Research
	Education and Awareness for Public / Society
	Education for Health Professionals
	Education for Individual/Patient
	Information or Resources
Going Beyond Western Healthcare	Choice
	Counselling
	Holistic & Alternate Care
Other	Not Specified



	Quote
	Women's* Health Understanding
Our Health	Addictions
	Age Specific
	Body Image
	Eating Disorder
	Reproductive Health
	Lived Experience
	Maternal and Postnatal Health
	Medication Effects
	Mental Health Labels and Experience
	Pain management
	Physical Health
	Receiving a Diagnosis
	Suicidal ideation
Person Centred and Humanistic Approaches	Collaboration
	Diminishing Experiences
	Diversity
	Equity
	Gender Diversity
	Humanistic Approach
	Mutuality
	Peer support
	Positive Experiences
	Power Imbalances
	Privacy, Risk and Security
	Socioeconomic Barriers
Trauma	
Prejudice, Self-Stigma and Discrimination	Fear
	Gender Based Discrimination
	Prejudice and discrimination



	Self-stigma
Service and System Improvements	ACC
	Access - Barrier
	Communication
	Cost - Barrier
	Funding
	Health System Resources - Infrastructure
	Health System Resources - Staff
	Preventative Care / Early Intervention and Diagnosis
	Staff Preference
	Wait times

3.1 Differences Between Delivery Formats

Data collected from the hui accounts for 44 per cent of responses, the online form accounts for 41 per cent of responses, eight per cent from the community whiteboard, and six per cent from social media or direct kōrero.

Hui	253
Believe Us	57
Person Centred and Humanistic Approaches	56
Service and System Improvements	46
Education and Awareness	28
Our Health	28
Prejudice, Self-Stigma and Discrimination	15
Going Beyond Western Healthcare	12
Culture and Community insights	7
Other	4
Survey	235
Service and System Improvements	63
Our Health	35
Person Centred and Humanistic Approaches	35
Believe Us	30



Going Beyond Western Healthcare	24
Education and Awareness	19
Other	11
Prejudice, Self-Stigma and Discrimination	11
Culture and Community insights	7
Community Whiteboard	46
Our Health	17
Service and System Improvements	12
Person Centred and Humanistic Approaches	6
Believe Us	5
Going Beyond Western Healthcare	3
Education and Awareness	2
Culture and Community insights	1
Social and Direct Kōrero	37
Believe Us	8
Person Centred and Humanistic Approaches	8
Service and System Improvements	8
Going Beyond Western Healthcare	6
Our Health	4
Education and Awareness	2
Prejudice, Self-Stigma and Discrimination	1



3.2 Thematic variance

Table 5: Thematic variance

	Other	Our Health	Person Centred	Service and System Improvements	Education and Awareness	Prejudice, Self-Stigma and Discrimination	Believe Us	Going Beyond Western Healthcare	Culture and Community insights
Other	0.04	0.10	0.13	0.14	0.08	0.05	0.12	0.07	0.04
Our Health	0.10	0.15	0.18	0.18	0.13	0.11	0.17	0.13	0.10
Person Centred and Humanistic Approaches	0.13	0.18	0.20	0.20	0.16	0.14	0.19	0.16	0.13
Service and System Improvements	0.14	0.18	0.20	0.21	0.17	0.15	0.20	0.16	0.14
Education and Awareness	0.08	0.13	0.16	0.17	0.11	0.09	0.15	0.11	0.08
Prejudice, Self-Stigma and Discrimination	0.05	0.11	0.14	0.15	0.09	0.07	0.13	0.09	0.05
Believe Us	0.12	0.17	0.19	0.20	0.15	0.13	0.19	0.15	0.12
Going Beyond Western Healthcare	0.07	0.13	0.16	0.16	0.11	0.09	0.15	0.10	0.07
Culture and Community insights	0.04	0.10	0.13	0.14	0.08	0.05	0.12	0.07	0.04

The table above describes at a thematic level, how individual feedback spoke to themes individually or together. Shown in green above, *person centred and humanistic approaches*, and *service and system improvement's* themes were often spoken of together, indicating a desired direction for healthcare improvements for women* in Aotearoa, but in the context of current experiences, this is also related to the *Believe Us* theme.



4. Theme Summaries

4.1 Believe Us

The theme *Believe Us* talks to a range of linked experiences of having your first-hand knowledge of what's happening to your health overshadowed. Some spoke of feelings of being “gaslit” or that “it’s all in your head”, while others spoke of having to decide “how presentable to look” before visiting a health provider and the need to weigh “being presentable enough” to be taken seriously, against visibly appearing “bad enough” to receive support. These sentiments appeared in conversations about both our physical and mental health.

Particularly in regard to reproductive or hormonal health these experiences were made more complex by the normalisation of pain or distressing reproductive or health experiences.

The individuals we spoke to often didn’t feel listened to or supported by the health system or their broader communities and society. The need to self-advocate considering these challenges was seen both as a necessity to access appropriate care, and an emotional and administrative burden.

“So, I don't think that we should be educating people that they have to advocate for their own healthcare. But then I kind of feel like we have to teach people how to advocate for their own health care if they want to get help.”

When *kōrero* was framed around improving experiences of women* with Lived Experience, being believed and listened to, as well as being offered informed choices surrounding our wellbeing were consistently prioritised.

4.2 Culture and Community Insights

Some participants shared insights from a specific cultural lens as well as a woman* with Lived Experience. These individuals spoke about cultural norms and expectations that make accessing healthcare information and support for both mental health experiences, such as depression and anxiety, and hormonal or reproductive health experience challenging.

Improving these experiences largely centred around accessible and appropriate cultural information and resources from a young age to break cycles of prejudice and self-stigma that many participants experienced themselves.

4.3 Education and Awareness

Building on this desire for better information and resources, feedback within the *Education and Awareness* theme can be divided into four areas.



Primarily, there was a strong desire from participants for health care providers to have more training and access to more information about the relationship between hormonal/reproductive health experiences and mental health. This lack of awareness was perceived as a considerable contributing factor to not feeling believed or trusted to understand our own health.

"[Doctors] understanding what could be and educating them to know that it's okay if they actually don't know the answer or what it is. I had a specialist and I told them I had a hysterectomy. And he [the Doctor] was like, "well, what was it for?" And I said, it was for [illness]. In my notes he put "she had a suspected hysterectomy". ...There's nothing suspected about it, I have a massive scar. I don't have a uterus. It's like, you know, and things like that."

Most participants who expressed concern about Doctor's understanding of physical and mental health experiences we have as women* with Lived Experience, did also acknowledge that health practitioner's ability to learn, and understand is currently constrained by the system we exist in. These constraints are discussed further under *Service and System Improvements*, but the relevant factors are the small health workforce, with limited access to specialists and very brief consultation times which all contribute to poor continuity of care and in depth understanding and awareness.

Conversations around education at an individual level, and for the public or society was targeted towards better education about what is normal, and challenging those expectations that create distress – such as periods are supposed to be painful or having to navigate poor experiences to learn for yourself how to advocate for better diagnostic processes.

"I haven't had really good experiences with health providers. But the best experiences are with women who take you seriously and respond with informative helpful information that is easily digestible."

Information and resourcing conversations created an interesting dichotomy. On one hand, individuals spoke about how the quality of our healthcare experience can be improved by having more thorough healthcare information that is available regardless of where you are seeking care – this was seen as a contrast to current experiences of shame when an individual isn't informed of what's in their medical history and distress at having to reiterate our stories and experiences.

However, others spoke to concerns around privacy and confronting experiences of having your full medical history accessible to health practitioners (including related services like pharmacies). In addition to this research, these concerns of privacy and information sharing is something Changing Minds navigates with members of the Lived Experience community



as this can contribute to diagnostic overshadowing – usually in the sense that mental health experiences become a barrier to receiving equitable physical health care.

4.4 Going Beyond Western / Medical Healthcare

Current experiences of healthcare weren't perceived by participants as offering informed choices and seen as favouring medical or pharmaceutical solutions to our health experiences.

"...I explained the situation was like, you know, everyone is different, and I don't feel that I need [anti-depressants]. And I had to talk to them about like my own mental health and saying like, yes I have bad days, but this is how I've come out and this is what I do, and things like that."

"My experience has been that women's pain levels and experience are often dismissed when presenting at emergency or GPs. Women often get a derogatory label or comments attached to medical notes about medical assistance sought. Even when treated".*

"Open minded & creative Drs who actively listen and care about finding the right solution for you."

People feel like there are currently barriers to accessing counselling or other talk therapies, as well as holistic approaches to care. Current access to these options were seen as short term, at best.

"Training for GPs and health professionals on how significant the effects of birth control or hormone imbalances are for wellbeing. More access to women's health services and a more holistic approach to healthcare"*

4.5 Our Health

Participant experiences of health in Aotearoa were diverse, but negative experiences were often attributed to diagnostic overshadowing, lack of awareness of certain conditions, or prejudice and discrimination against mental distress or addictions. Many participants felt that their physical appearance – often their weight – significantly impacted the quality of their care, and in some instances was actively harmful to their health.

"There is not enough understanding, communication or education around perimenopause and menopause. I feel like I am going through the emotional rollercoaster of puberty again yet having to hold down a job and family while



feeling brain dead and crazy - NOBODY talks about this stuff, and how those of us with Lived Experience are more likely to get hit hardest by it.”

“As a person that has lived with endo for over 20 years and most recently being diagnosed with PTSD due to medical trauma, having to advocate for help and better healthcare.”

“But also, the weight issue that [people with addictions] are known for people been underweight and looking deathly and skeletal. Doctors were very reluctant to believe that I didn't have an overeating problem and didn't although they didn't have all the facts they did and the weight issues for me were never fairly judged.”

“The neurologists who spent the whole time talking about my BMI instead of focusing about all the ticks and the tremors and stuff my body was happening.”

“It's very easy for everyone to point the finger at PTSD and say it's the cause of all my issues. Even when my PTSD is improving but my physical health is declining sharply.”

“If another doctor asks, 'do you think it could be menopause?' I may scream. There seems to be very rigid thinking, or a lack of thinking, about women's health. Many doctors/clinicians assume there is sexual abuse issues if they hear PTSD. I feel there is reluctance to do a full physical examination because I have a female body, like I am fragile, or they may be accused of misconduct.”

“Even the fact that the pain management doctor had put that I was with diagnosed with an eating disorder that [another doctor] was telling me to put to lose more weight and to cut back on my eating because I'm obese and things like that.”

“Teach health professionals about all mental health disorders, including OCD, eating disorders and other illness' with stereotypes that are swept under the rug.”

4.6 Person Centered and Humanistic Approaches

“We need to do that journey together and there's no understanding of that.”



Overwhelmingly participants spoke about desires for person centred and humanistic approaches to healthcare in Aotearoa. When asked what would make experiences better, or improve healthcare people spoke of enshrining compassion, empathy, integrity and equity. Individuals spoke of wanting to be seen as a whole person and being listened to – addressing some of the concerns expressed under the ‘believe us’ theme.

This looks like healthcare providers being appropriately resourced and supported to build a continuity of care with an individual, more time to listen and understand their experiences and to take a collaborative approach to health diagnosis, note taking and health interventions.

“Medical professionals who have the time to listen to their patients. Patients being treated as real people.”

“Feeling heard, not rushed, take the time to read the notes about me and my history, come to an appointment with understanding and empathy, I am not a robot, and neither are you.”

“Being listened too. Being seen as an individual. Being respected for the wisdom I bring in regard to my diseases. Being trusted. Collaboration.”

Those who spoke of a humanistic approach to care also often spoke of the need to address power imbalances that are currently created within a “specialist - patient” dynamic, which undermine our individual knowledge and experiences.

“But we sort of have this idea like people think you should have a psychiatrist. I don't have one and I've got bipolar, and I'm actually fine.”

“It's they're the ones with the power, they're the ones who have the knowledge and yes, they do. But they don't have the knowledge that know about me.”

People want health providers to be aware of some of the specific needs we may have as women* with Lived Experience, including not feeling safe within the system, being transient or experiencing unsafe home environments, understanding of the interaction between our hormonal health, mental health and other health experiences, available time to seek treatment, and fears of being judged.



“Unfortunately, I find the healthcare system isn't set up to support our wahine. GPs lack knowledge on women's issues like endometriosis, women's pain is belittled and ignored, services for hapu wahine are under resources and healthcare staff lack knowledge of trauma informed care and how to provide healthcare to survivors of sexual assault. My lived experience as a queer wahine Māori with endometriosis/chronic pain, infertility struggles, and history of sexual assault has meant the healthcare system feels unsafe and actually a dangerous place for me to be. In the last year I have been diagnosed with PTSD following an experience being mistreated by staff at a public hospital. I am scared of seeking medical treatment and frightened and mistrustful of medical professionals.”

“[I'm] less likely to seek medical help due to timeframes, being doubted, being judged.”

“More time. Appreciate the things I write down when I struggle to communicate. Appreciate the Complexity of my health. Don't go for the easy option.”

“You really do need those peer support workers out there who can assist you when you've got mental health stuff because they need to understand.”

“So there was no there was no continuity of care with any doctors because you were either transient... if an initial appointment was made, it was never followed through”

4.7 Prejudice, Self-stigma, and Discriminations

Prejudice, self-stigma, and discrimination were noted as being both barriers to seeking healthcare and challenges women* with Lived Experience face within our health system. In most instances participants felt that this could be best improved through education for health practitioners and for the public as well as taking steps towards a person-centred health care and humanistic healthcare model that understands, listens to, and believes the individual.

“As an ethnically diverse woman with lived experience, I find that my interactions when seeking healthcare for myself are often generalised and not prioritised. I often get stereotyped as a model minority and these implications on health.”



“Similar [mental distress experience] happened with my older brother as well. But they were - they listened to him more and they were more. I don't know. I just felt like there was a difference in the way that I was treated compared to my older brother so yeah.”

“I'm weary of doctors & know that as people they hold stigma too.”

“So I get a lot of anxiety about seeing new specialists that don't know me or going into a new appointment where you know, it's not my regular kind of. Because from having all that judgment from things being said to me over the last few years, I don't know how [they're] going to react”?

“Not loving myself, the self-punishment that came without taking care of myself and following through with doctor's advice and things.”

“But then also, you know, educating, you know, the wider the wider New Zealand you know, like, almost like media campaigns to break the stigma around menstruation and understanding of life.”

4.8 Service and System Improvements

It is unsurprising then, as we see in Table 5 that *service and system improvements* and *person centred, and humanistic approaches* were likely to be spoken of in the same kōrero.

Person centred and humanistic principles were acknowledged as an important tool not only to improve the experiences of women* with Lived Experience, but also to enhance the practice and experiences of health professionals by reducing burdens on their time and resources.

“A more joined up system where healthcare professionals have the time to support the needs of their individual patients and are not overworked and under resourced. In my experience, specific areas that need help are endometriosis, midwifery/obstetrics and mental health services including mother and baby in-patient units.”

Some of the pain points of the current system were recognised as making experiences of mental distress worse:



“So, what may start off as sort of low level mental distress situation, it's just like this helplessness [within the system], but this sort of feeling of just wanting to scream.”

“Better rested healthcare staff. It's hard to be compassionate if you're stretched.”

“Going to your GP when you need help and not being listened to at all is very common. We need GPs that take the time to listen to people, and that acknowledge that they don't know everything, and that's ok. GPs need to be given time to read notes and often due to how hard it can be to get appointments to see a GP, often people see various doctors in a medical centre, this can be a disadvantage to them as they don't have that "bond" with their GP, that one GP does not know them or their history.”

People spoke of wait times to access healthcare services, and specialist services, as well as the impact of delayed or difficult processes to receive a diagnosis. There was an acknowledgement that we need both funding for specialist mental health services, and reproductive/hormonal health services in addition to better infrastructure funding and support for the health system as a whole.

“Women are unfortunately treated as second class citizens by Aotearoa's healthcare system. Women's issues like endometriosis and PCOS are too often brushed aside, with GPs lacking knowledge and providing little or no support in these areas. Women's pain isn't believed. Women's health services like midwives and hospital labour and delivery departments are under resources, delivering downright dangerous outcomes for wahine. Maternal mental health services are shocking and extremely hard to access. Our women deserve better.”

To make accessing services feel safer, many spoke about the benefit of seeing a female health practitioner, or seeing a practitioner you identify with, and increasing access to peer support or talk therapies within the health system.

“The best health care that I've received has come from other women. Practice nurses, midwives. They often have much better communication than male GP. I find getting information regarding health and contraception from a good practice nurse so valuable.”

“One of my conditions that I have, pretty much all other practitioners are males, but there is no, there's no female practitioners who specialize in this particular area.”



“But the best experiences are with women who take you seriously and respond with informative helpful information that is easily digestible.”

4.9 Code Correlations

4.9.1 Believe Us – Theme Code Correlations.

The following table tells us that people who spoke to concerns of not being believed, or desires to be believed were also most likely (27%) to talk to experiences of health issues being normalised.

	Diagnostic Overshadowing	Feeling - Being Believed	Feeling - Isolation	Feeling - Listened To	Feeling - Supported	Normalisation	Self-Advocacy
Diagnostic Overshadowing	100%						
Feeling - Being Believed	-6%	100%					
Feeling - Isolation	-1%	-2%	100%				
Feeling - Listened To	-5%	0%	-1%	100%			
Feeling - Supported	-3%	-6%	-1%	3%	100%		
Normalisation	-2%	27%	0%	-2%	-2%	100%	
Self-Advocacy	-4%	2%	-1%	1%	-4%	-2%	100%

4.9.2 Our Health – Theme Code Correlation

When individuals spoke about health concerns, we see a cluster of issues:

- Medication effects and reproductive health (which topics such as birth control).
- Lived Experience and mental health diagnoses.
- Reproductive health and mental health diagnoses.

	Addictions	Age Specific	Body Image	Eating Disorder	Reproductive Health	Lived Experience	Maternal and Post Natal Health	Medication Effects	Mental Health Diagnosis	Pain management	Physical Health	Receiving a Diagnosis	Suicidal Ideation
Addictions	100%	0%	-1%	0%	-1%	-1%	-1%	0%	-1%	-1%	-1%	-1%	0%
Age Specific	0%	100%	-1%	0%	-1%	-1%	-1%	0%	-1%	-1%	-1%	-1%	0%
Body Image	-1%	-1%	100%	-1%	-3%	-2%	-2%	-1%	-2%	-1%	-1%	-1%	-1%
Eating Disorder	0%	0%	-1%	100%	-2%	-1%	-1%	0%	17%	-1%	-1%	-1%	0%
Reproductive Health	-1%	-1%	-3%	-2%	100%	-5%	4%	21%	18%	9%	-3%	7%	-1%
Lived Experience	-1%	-1%	-2%	-1%	-5%	100%	-3%	-1%	31%	-2%	-2%	-2%	-1%



Maternal and Post Natal Health	-1%	-1%	-2%	-1%	4%	-3%	100%	-1%	-3%	-2%	-2%	-2%	-1%
Medication Effects	0%	0%	-1%	0%	21%	-1%	-1%	100%	-1%	-1%	-1%	-1%	0%
Mental Health Diagnosis	-1%	-1%	-2%	17%	18%	31%	-3%	-1%	100%	-2%	-3%	9%	-1%
Pain management	-1%	-1%	-1%	-1%	9%	-2%	-2%	-1%	-2%	100%	21%	-1%	-1%
Physical Health	-1%	-1%	-1%	-1%	-3%	-2%	-2%	-1%	-3%	21%	100%	-1%	-1%
Receiving a Diagnosis	-1%	-1%	-1%	-1%	7%	-2%	-2%	-1%	9%	-1%	-1%	100%	-1%
Suicidal ideation	0%	0%	-1%	0%	-1%	-1%	-1%	0%	-1%	-1%	-1%	-1%	100%

4.9.3 Inter-theme code correlations

At a code level, a full table of the correlations is included in appendix one. This shows both the relationship between codes within a theme, and the relationship between codes across themes.



5. How Does Your Experiences as a Woman* With Lived Experience Impact Your Experience of Healthcare?

Believe Us

Diagnostic Overshadowing

It's very easy for everyone to point the finger at PTSD and say it's the cause of all my issues. Even when my PTSD is improving but my physical health is declining sharply.

Feeling - Being Believed

Believe they (ppl in the system) need to realise it too.

I barely go to the doctor until it's really necessary. I don't trust doctors and I never see male doctors unless I don't have a choice

Feeling - Listened To

I get impatient when a Dr isn't listening to the person who knows their body best (me)

Self-Advocacy

As a person that has lived with endo for over 20years and most recently being diagnosed with PTSD due to medical trauma, having to advocate for help and better health care, I have a good understanding of how our medical system works.

Because I have had doctors tell me what I am, I have been forced to advocate for myself and push to get what I need.

I get impatient when a Dr isn't listening to the person who knows their body best (me)

Culture and Community insights

Deaf Community Insights

Many deaf women miss out on healthcare due lack of information in sign language.

Education and Awareness

Education for Health Professionals

GPs do not understand contraceptive properly. They simply "don't know" how it impacts other medication, and don't look at how long you have been on it. Also, the mental and physical side effects of other drugs, especially the lack of hormonal effects and information.

I am severely disappointed with the New Zealand health system, especially around mental health, there is literally no knowledge of OCD here and ADHD is treated like a joke. The only thing taken seriously here is depression.



Unfortunately, I find the healthcare system isn't set up to support our wahine. GPs lack knowledge on women's issues like endometriosis, women's pain is belittled and ignored, services for hapu wahine are under resources and healthcare staff lack knowledge of trauma informed care and how to provide healthcare to survivors of sexual assault. My lived experience as a queer wahine Māori with endometriosis/chronic pain, infertility struggles, and history of sexual assault has meant the healthcare system feels unsafe and actually a dangerous place for me to be. In the last year I have been diagnosed with PTSD following an experience being mistreated by staff at a public hospital. I am scared of seeking medical treatment and frightened and mistrustful of medical professionals.

Information or Resources

I have not felt any discrimination because I am a woman, but I don't the appropriate resources are out there for women generally.

Going Beyond Western Healthcare

Holistic & Alternate Care

Less likely to seek medical help due to timeframes, being doubted, being judged. More likely to see holistic and Complimentary treatments than mainstream

As an ethnically diverse woman with lived experience, I find that my interactions when seeking healthcare for myself are often generalised and not prioritised. I often get stereotyped as a model minority and these implications on health

Our Health

Hormonal and Reproductive Health

As a person that has lived with endo for over 20years and most recently being diagnosed with PTSD due to medical trauma, having to advocate for help and better health care, I have a good understanding of how our medical system works.

GPs do not understand contraceptive properly. They simply "don't know" how it impacts other medication, and don't look at how long you have been on it. Also, the mental and physical side effects of other drugs, especially the lack of hormonal effects and information.

If another doctor asks, 'do you think it could be menopause?' I may scream. There seems to be very rigid thinking, or a lack of thinking, about women's health. Many doctors/clinicians assume there is sexual abuse issues if they hear PTSD. I feel there is reluctance to do a full physical examination because I have a female body, like I am fragile, or they may be accused of misconduct.

Lived Experience

Believe they (ppl in the system) need to realise it too.



I think I've been lucky, but it's hard to be taken seriously when sharing my expertise

Lived experience means I often don't earn as much as my peers which then limits my access to healthcare, esp. dentist, but also additional treatments e.g., mole check \$400.

Maternal and Post Natal Health

As a mother there are expectations on you to be or act a certain way. Questions you are asked that a male/father would be unlikely to be asked.

Medication Effects

GPs do not understand contraceptive properly. They simply "don't know" how it impacts other medication, and don't look at how long you have been on it. Also, the mental and physical side effects of other drugs, especially the lack of hormonal effects and information.

Mental Health Diagnosis

As a person that has lived with endo for over 20years and most recently being diagnosed with PTSD due to medical trauma, having to advocate for help and better health care, I have a good understanding of how our medical system works.

I am severely disappointed with the New Zealand health system, especially around mental health, there is literally no knowledge of OCD here and ADHD is treated like a joke. The only thing taken seriously here is depression.

If another doctor asks, 'do you think it could be menopause?' I may scream. There seems to be very rigid thinking, or a lack of thinking, about women's health. Many doctors/clinicians assume there is sexual abuse issues if they hear PTSD. I feel there is reluctance to do a full physical examination because I have a female body, like I am fragile, or they may be accused of misconduct.

It's very easy for everyone to point the finger at PTSD and say it's the cause of all my issues. Even when my PTSD is improving but my physical health is declining sharply.

Lived experience means I often don't earn as much as my peers which then limits my access to healthcare, esp. dentist, but also additional treatments e.g., mole check \$400.

Receiving a Diagnosis

As a person that has lived with endo for over 20years and most recently being diagnosed with PTSD due to medical trauma, having to advocate for help and better health care, I have a good understanding of how our medical system works.

Person Centred and Humanistic Approaches

Diminishing Experiences

GPs do not understand contraceptive properly. They simply "don't know" how it impacts other medication, and don't look at how long you have been on it. Also the mental and physical side effects of other drugs, especially the lack of hormonal effects and information.



Diversity

Unfortunately, I find the healthcare system isn't set up to support our wahine. GPs lack knowledge on women's issues like endometriosis, women's pain is belittled and ignored, services for hapu wahine are under resources and healthcare staff lack knowledge of trauma informed care and how to provide healthcare to survivors of sexual assault. My lived experience as a queer wahine Māori with endometriosis/chronic pain, infertility struggles, and history of sexual assault has meant the healthcare system feels unsafe and actually a dangerous place for me to be. In the last year I have been diagnosed with PTSD following an experience being mistreated by staff at a public hospital. I am scared of seeking medical treatment and frightened and mistrustful of medical professionals.

Gender Diversity

As a mother there are expectations on you to be or act a certain way. Questions you are asked that a male/father would be unlikely to be asked.

Humanistic Approach

Less likely to seek medical help due to timeframes, being doubted, being judged. More likely to see holistic and Complimentary treatments than mainstream

still an overarching hangover of patriarchal overtones, hysteria, that either our feelings are "normal" (no they are not) or we're hypochondriacs (nope - wrong again) hormonal changes, over-responsibility and stress are real and affect our mental health

Positive Experiences

Sceptical of how the system with the government works now as I didn't feel cared for. However, I found luck in my GP who was amazingly helpful

Power Imbalances

I think I've been lucky, but it's hard to be taken seriously when sharing my expertise

Socioeconomic Factors

I have a history of depression and anxiety stemming from an infidelity in my marriage. I suffered a major depressive episode because of this. I think this experience has made me more aware of how trauma can impact women's* ongoing health problems.

Lived experience means I often don't earn as much as my peers which then limits my access to healthcare, esp. dentist, but also additional treatments e.g., mole check \$400.

Trauma

As a person that has lived with endo for over 20years and most recently being diagnosed with PTSD due to medical trauma, having to advocate for help and better health care, I have a good understanding of how our medical system works.

I have a history of depression and anxiety stemming from an infidelity in my marriage. I suffered a major depressive episode because of this. I think this experience has made me more aware of how trauma can impact women's* ongoing health problems.



If another doctor asks 'do you think it could be menopause?' I may scream. There seems to be very rigid thinking, or a lack of thinking, about women's health. Many doctors/clinicians assume there is sexual abuse issues if they hear PTSD. I feel there is reluctance to do a full physical examination because I have a female body, like I am fragile, or they may be accused of misconduct.

Unfortunately, I find the healthcare system isn't set up to support our wahine. GPs lack knowledge on women's issues like endometriosis, women's pain is belittled and ignored, services for hapu wahine are under resources and healthcare staff lack knowledge of trauma informed care and how to provide healthcare to survivors of sexual assault. My lived experience as a queer wahine Māori with endometriosis/chronic pain, infertility struggles, and history of sexual assault has meant the healthcare system feels unsafe and actually a dangerous place for me to be. In the last year I have been diagnosed with PTSD following an experience being mistreated by staff at a public hospital. I am scared of seeking medical treatment and frightened and mistrustful of medical professionals.

Prejudice, Self-Stigma and Discrimination

Fear

Unfortunately, I find the healthcare system isn't set up to support our wahine. GPs lack knowledge on women's issues like endometriosis, women's pain is belittled and ignored, services for hapu wahine are under resources and healthcare staff lack knowledge of trauma informed care and how to provide healthcare to survivors of sexual assault. My lived experience as a queer wahine Māori with endometriosis/chronic pain, infertility struggles, and history of sexual assault has meant the healthcare system feels unsafe and actually a dangerous place for me to be. In the last year I have been diagnosed with PTSD following an experience being mistreated by staff at a public hospital. I am scared of seeking medical treatment and frightened and mistrustful of medical professionals.

Gender Based Discrimination

If another doctor asks 'do you think it could be menopause?' I may scream. There seems to be very rigid thinking, or a lack of thinking, about women's health. Many doctors/clinicians assume there is sexual abuse issues if they hear PTSD. I feel there is reluctance to do a full physical examination because I have a female body, like I am fragile, or they may be accused of misconduct.

still an overarching hangover of patriarchal overtones, hysteria, that either our feelings are "normal" (no they are not) or we're hypochondriacs (nope - wrong again) hormonal changes, over-responsibility and stress are real and affect our mental health

Prejudice and discrimination

As an ethnically diverse woman with lived experience, I find that my interactions when seeking healthcare for myself are often generalised and not prioritised. I often get stereotyped as a model minority and these implications on health



I'm weary of doctors & know that as people they hold stigma too

Less likely to seek medical help due to timeframes, being doubted, being judged. More likely to see holistic and Complimentary treatments than mainstream

Service and System Improvements

Access - Barrier

Many deaf women miss out on healthcare due lack of information in sign language.

Cost - Barrier

Lived experience means I often don't earn as much as my peers which then limits my access to healthcare, esp. dentist, but also additional treatments e.g., mole check \$400.

With GP care, not at all other services like community mental health, private psychologists and psychiatry are very expensive and often not helpful

Health System Resources - Infrastructure

I am severely disappointed with the New Zealand health system, especially around mental health, there is literally no knowledge of OCD here and ADHD is treated like a joke. The only thing taken seriously here is depression.

I expect a lot of the health system as I'm aware of how much influence they have

Sceptical of how the system with the government works now as I didn't feel cared for. However, I found luck in my GP who was amazingly helpful

Unfortunately, I find the healthcare system isn't set up to support our wahine. GPs lack knowledge on women's issues like endometriosis, women's pain is belittled and ignored, services for hapu wahine are under resources and healthcare staff lack knowledge of trauma informed care and how to provide healthcare to survivors of sexual assault. My lived experience as a queer wahine Māori with endometriosis/chronic pain, infertility struggles, and history of sexual assault has meant the healthcare system feels unsafe and actually a dangerous place for me to be. In the last year I have been diagnosed with PTSD following an experience being mistreated by staff at a public hospital. I am scared of seeking medical treatment and frightened and mistrustful of medical professionals.

Staff Preference

Less likely to seek medical help due to timeframes, being doubted, being judged. More likely to see holistic and Complimentary treatments than mainstream

Wait times

- I can get very stressed/anxious when put on a wait list not knowing when I will get treatment (exacerbates the situation e.g., my mental health). - with counselling/talk therapy, by the time things have got so bad that I see the GP, having to go on a waitlist, my MH has really dipped.



Less likely to seek medical help due to timeframes, being doubted, being judged. More likely to see holistic and Complimentary treatments than mainstream



7. If You Were Designing the Health System What Would Your Top Three Priorities Be?

Count	Priority One	Count	Priority Two	Count	Priority Three
10	Service and System improvements	6	Service and System improvements	7	Service and System improvements
6	Going Beyond Western/Medical Healthcare	4	Our Health	3	Believe Us
5	Believe Us	3	Going Beyond Western/Medical Healthcare	3	Culture and Community
5	Person Centred and Humanistic Approaches	3	Other	3	Person Centred and Humanistic Approaches
4	Education and Awareness	2	Person Centred and Humanistic Approaches	1	Education and Awareness
2	Our Health	1	Believe Us	1	Going Beyond Western/Medical Healthcare
1	Culture and Community	1	Education and Awareness	1	Other
1	Prejudice, Self-stigma, and Discrimination	1	Prejudice, Self-stigma, and Discrimination	1	Our Health
				1	Prejudice, Self-stigma, and Discrimination

When we asked what participants' what their priorities would be if they could design a health system, it is unsurprising that the service and system improvements ranked highest overall. Some of the existing pain points that the community identified as opportunities for improvement are already well known. These include:

- **Minimising wait times** to see a health practitioner and reducing wait times to receive a diagnosis (for either physical or mental health).



- **Addressing barriers to access.** There is a cross over here with wait times, particularly to see specialists, but most people spoke of physical, technological, or administrative barriers to access.
- **Increasing Health Practitioner staffing.** This was seen as a critical way to address concerns around:
 - continuity of care,
 - wait times to see a practitioner or specialist,
 - support for a more humanistic approach to healthcare, where the practitioner and the individual have longer and/or more regular consultations. This would enable a deeper understanding of the person's health issues.

Participants saw lack of service funding and the cost of accessing healthcare as significant barriers.



8. What Makes Health Experiences Feel Positive and Supportive?

From eight identified themes, three key themes emerged.

- Believe Us – Four central codes.
 - Feeling – Being Believed.
 - Feeling – Listened To.
 - Feeling – Supported.
 - Self-Advocacy.
- Person Centred and Humanistic Approaches
 - Humanistic Approaches.
 - Power Imbalances.
- Going Beyond Western Healthcare

Very few participants explicitly mentioned positive experiences of health care in Aotearoa (n=2), however many spoke about what would make experiences better.

8.1 Being Believed

Feelings of not being believed, or an individual's expertise in their health experiences were common across all questions, and open feedback. However, when considering what makes experiences feel positive and supportive, feeling listened to by the health practitioner was key.

Participants identified that the burden on health practitioners, particularly GPs, to fit consultations into 15 – 30-minute sessions is resulting in poor experiences as this can feel like practitioners don't understand your health history.

“Being listened too. Being seen as an individual. Being respected for the wisdom I bring regarding my diseases. Being trusted.”

“Medical professionals who have the time to listen to their patients. Patients being treated as real people.”

“Going to your GP when you need help and not being listened to is very common. We need GPs that take the time to listen to people, and that acknowledge that they don't know everything, and that's ok. GPs need to be given time to read notes and due to how hard it can be to get appointments to see a GP, people see various doctors in a medical centre, this can be a disadvantage as they don't have that "bond" with their GP, they do not know them or their history.”



8.2 Person Centered and Humanistic Approaches

Ideas around being listened to or believed are also present in comments relating to person centered or humanistic approaches.

“Good communication. Being able to ask questions and seek out good information from the provider, being truly listened to, and taken seriously when you describe mental or physical symptoms.”

“Open minded & creative Drs who actively listen and care about finding the right solution for you.”

“Feeling heard, not rushed, take the time to read the notes about my history, come to an appointment with understanding and empathy, I am not a robot, and neither are you.”

“Being listened to - knowing your primary care provider has option B available if the wait time is too high. e.g., ‘we are in this together’.”

8.3 Going Beyond Western / Medical Models of Healthcare

Choice

“Being believed, being offered choice”.

“Being listened to, and informed of ALL info (diagnoses/ treatments etc)”

“When services and kaimahi look like me and feel like safe people who understand my experience. having the right and autonomy to be informed and choose”.

“Accessibility - able to get an appointment when I need it; a doctor who has time to listen and isn't rushing through the appointments. Other suggestions other than medication e.g., nutrition, exercise, access to counselling”

Holistic & Alternate Care

“Being listened to, not being rushed to solve and issue within 15 mins, offering more choice that isn't about medication”.



“Open minded & creative Drs who actively listen and care about finding the right solution for you”.

Appendix One: Code Correlations Across Themes

	Believe Us	Culture and Community Insights	Education and Awareness	Going Beyond Western Healthcare	Other	Our Health	Person Centred and Humanistic Approaches	Prejudice, Self-Stigma and Discrimination	Service and System Improvements
Diagnostic Overshadowing Feeling - Being Believed Feeling - Isolation Feeling - Listened To Feeling - Supported Normalisation Self Advocacy	100%	-1%	-2%	-2%	-2%	-2%	-2%	-2%	-2%
	-2%	-4%	-1%	-3%	-2%	-1%	-3%	-2%	-1%
	-1%	-2%	100%	-1%	-1%	0%	-1%	-1%	-1%
	-5%	0%	100%	3%	-2%	1%	-3%	-2%	-1%
	-3%	-6%	-1%	-3%	-2%	-4%	-2%	-4%	-2%
Culture Deaf Community Insights Current & Best Practice Research Education and Awareness for Public / Society Education for Health Professionals Education for Individual/Patient Information or Resources	-3%	-5%	-1%	-3%	-2%	-1%	-3%	-2%	-1%
	-2%	-4%	-1%	-3%	-2%	-1%	-3%	-2%	-1%
	-2%	-3%	0%	-2%	-1%	-2%	-1%	-1%	-1%
	-1%	-2%	0%	-2%	-1%	-2%	-1%	-1%	-1%
	-1%	-2%	0%	-2%	-1%	-2%	-1%	-1%	-1%
Choice Counselling Holistic & Alternative Care Not Specified Quote Women's Health Understanding Additions Age Specific Body Image Eating Disorder Gynaecological Health Lived Experience Maternal and Post Natal Health Mental Health Diagnosis Pain management Physical Health Receiving a Diagnosis Social Isolation	-3%	-6%	-1%	-3%	-2%	-1%	-3%	-2%	-1%
	-2%	-4%	-1%	-3%	-2%	-1%	-3%	-2%	-1%
	-3%	-6%	-1%	-3%	-2%	-1%	-3%	-2%	-1%
	-1%	-2%	0%	-2%	-1%	-2%	-1%	-1%	-1%
	-1%	-2%	0%	-2%	-1%	-2%	-1%	-1%	-1%
Collaboration Diminishing Experiences Diversity Equity Gender Diversity Humanistic Approach Mutuality Peer support Positive Experiences Power Imbalances Privacy, Risk and Security Socioeconomic Barriers Trauma	-2%	-3%	0%	-2%	-1%	-2%	-1%	-2%	-1%
	-2%	-3%	0%	-2%	-1%	-2%	-1%	-2%	-1%
	-2%	-3%	0%	-2%	-1%	-2%	-1%	-2%	-1%
	-2%	-3%	0%	-2%	-1%	-2%	-1%	-2%	-1%
	-2%	-3%	0%	-2%	-1%	-2%	-1%	-2%	-1%
Fear Gender Based Discrimination Prejudice and Discrimination Self stigma ACC Access - Barrier Communication Cost - Barrier Funding Health System Resources - Infrastructure Health System Resources - Staff Preventative Care / Early Intervention and Diagnosis Staff Preference Wait times	-1%	-2%	0%	-1%	-1%	-1%	-1%	-1%	-1%
	-3%	-5%	-1%	-3%	-2%	-1%	-3%	-2%	-1%
	-3%	-5%	-1%	-3%	-2%	-1%	-3%	-2%	-1%
	-4%	-7%	-1%	-5%	-2%	-1%	-5%	-2%	-1%
	-5%	-8%	-1%	-5%	-2%	-1%	-5%	-2%	-1%