

Consumer Participation Framework

“Valuing and respecting the lived experience voice”



Health outcomes are enhanced by genuine consumer participation at all levels

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Introduction

This framework is aimed at Mental Health and Addictions services and staff to help them to understand what Consumer Participation is and to explore ways to effectively facilitate consumer engagement/participation in all levels of the organization.

Page 1: This framework has been developed to strengthen the consumer voice in Mental Health and Addictions service delivery by ensuring that people with lived experience of Mental Health and/or addictions are involved in the planning, implementation and evaluation of Mental Health and Addictions services at all levels. The framework is grounded in the 10 principles of Te Ara Tauwhirotaunga – ‘Pathways that lead us to act with kindness’ which is the model of care for MH&A services in Lakes. The focus areas are the three levels of an organization that consumer participation will occur – ‘Direct Care’, ‘Service Design and Delivery’ and, ‘Governance Strategy and Policy Development’.

Page 2: The continuum of Consumer Participation describes what engagement will look like at each level of the organization and how this relates to Te Tiriti o Waitangi. For example – ‘Partnership and Shared Leadership’ is considered the gold standard for consumer engagement at all levels of the organization. At the Direct Care level *“Treatment and care decisions are made together based on the Consumer’s preferences, medical evidence and clinical judgement”*. The overall vision for this framework is to ensure that the lived experience voice is valued and respected. Specific themes from Te Ara Tauwhirotaunga have been used to demonstrate how services can achieve this.

Page 3: There are many local, regional and national documents that discuss the importance of and guide effective consumer participation. These have been summarised and collated to outline what consumer participation looks like (or means) at each level of the organisation, what the benefits are for consumers and for staff and the organisation, what barriers there may be and how these could possibly be overcome,

Page 4: Lastly, there is a list of resources that may be of some use to services and to staff if they want to know more about consumer participation at a systemic level.

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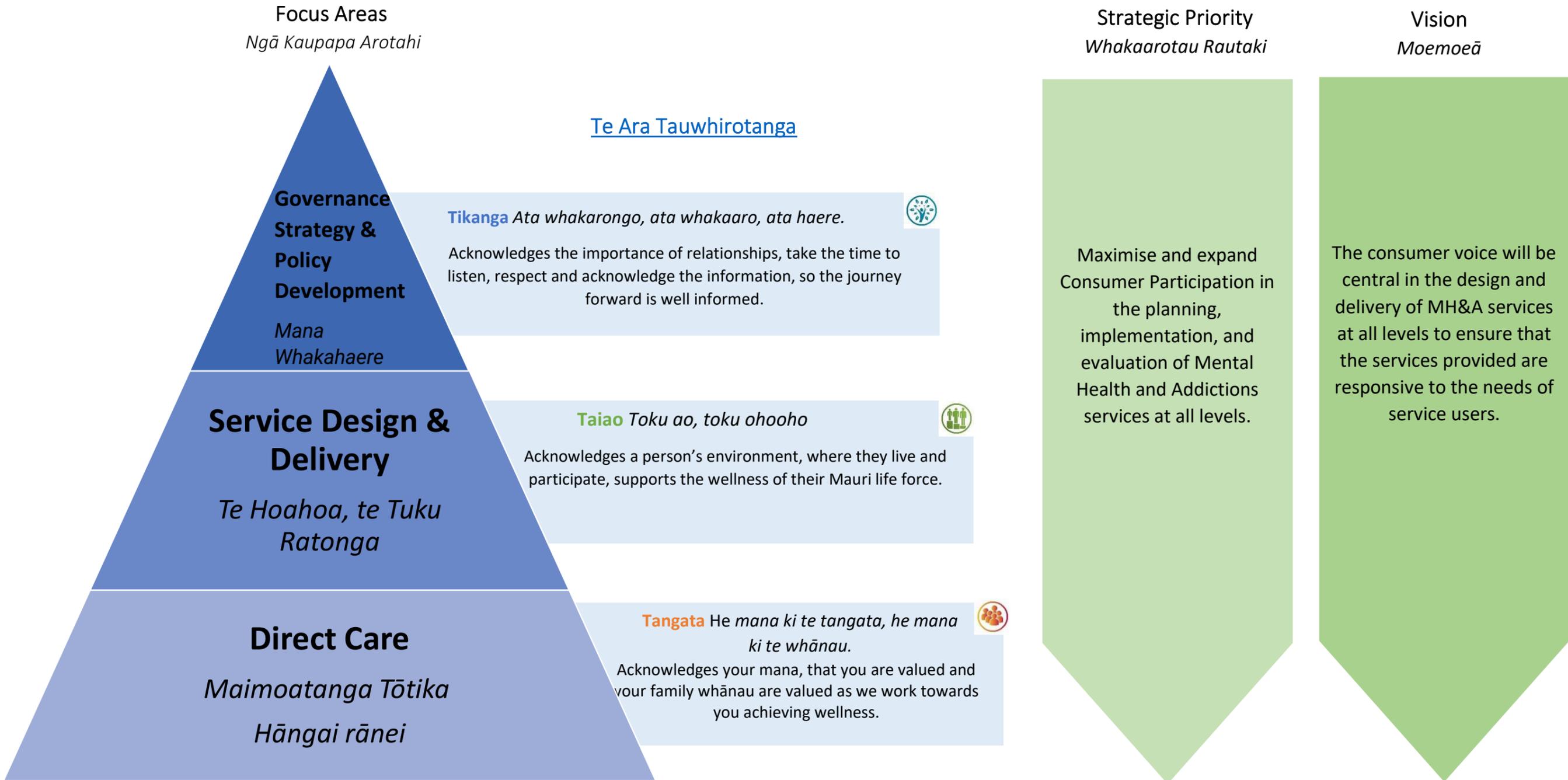
My experience matters
He Take tō Aku Wheako

Connectedness
Te Tūhononga

Te Ao Maori Worldview
Te Tirohanga (Māori)

Healing and Recovery
Te Whakamahu, te Whakaora

Protecting and promoting wellbeing
Te tiaki, te whakatairanga oranga



Family/whanau as partners
Hai (Hei) hoa rangapū

Caring & well supported workforce
Te hunga kaimahi ka tiakina, ka tautokona

Easy quick access to help
He ngāwari, he tere te āheinga āwhina

Local service presence
He ratonga kāinga ka kitea

Equitable outcomes
Ngā Putanga Tautika

Continuum of Consumer Participation

Levels of Engagement <i>Ngā Taumata Whai Wāhi</i>	Consultation <i>Te Uiuinga Mātanga</i>	Involvement <i>Te Whakaurunga</i>	Partnership and Shared Leadership <i>Te Hautūtanga ā-Rangapū, ā-Mahi Tahī</i>
DIRECT CARE <i>Maimoatanga Tōtika Hāngai rānei</i>	*Consumers receive information about a diagnosis and treatment options	Consumers are asked about their preferences in treatment plan and their chosen supports	Treatment and care decisions are made together based on the Consumer’s preferences, medical evidence and clinical judgement <i>“Nothing about me, without me”</i>
SERVICE DELIVERY AND DESIGN <i>Te Hoahoa, te Tuku Ratonga</i>	Surveys and focus groups are undertaken to ask consumers about their experiences of the services	*People with lived experience of Mental Health and Addictions are involved as advisors and facilitators e.g., Consumer Advisory Group members	People with lived experience are involved and valued in all co-design of Mental Health and Addictions improvement initiatives and service planning
DECISION MAKING IN GOVERNANCE, STRATEGY AND POLICY DEVELOPMENT <i>Te Whakatau Take i te Mana Whakahaere, Te Whanaketanga Rautaki, Kaupapa Here</i>	Focus groups held with key consumer groups to understand personal experience when accessing health care options	Consumer recommendations are used to make key organisational planning and funding decisions	Consumers/People with lived experience are represented on decision making committees and boards about how service models are created and about allocation of health care resources
HOW THIS RELATES TO TE TIRITI O WAITANGI <i>Te pānga o tēnei ki Te Tiriti</i>	Partnership and Shared Leadership enables service delivery on all levels to put into action the following principles of Te Tiriti o Waitangi, as described in Whakamaua (the Māori Health Action Plan 2020–2025): (1) Tino Rangatiratanga (Authority, Autonomy and Control over resources), (2) Equity, (3) Active Protection, (4) Options and (5) Partnership		



Valuing the lived experience voice

Kia uaratia te reo wheako

“When I am a part of the workforce, my lived experience can support others in their healing journey”.

“Mutual respect and trust can develop from listening to and valuing what is happening for me”.

“Concepts that I recognize such as whakapapa, tikanga and kawa are woven into all service delivery”.

“Connecting with services takes courage and effort”.

*Person with lived experience, service user or consumer - A person with lived experience, a service user or a consumer is a person who accesses, or has accessed, services for mental health and/or addiction needs.

<p style="text-align: center;">DIRECT CARE</p>	<p>What does this mean?</p> <ul style="list-style-type: none"> Asking what matters to you? and being interested and valuing the answers. Provide opportunity for shared decision making, i.e., care and discharge planning. Listening and valuing the consumers understanding of what is happening to them. Collaborative notetaking. Bedside or warm handovers involving consumers, family/whānau become the norm. Encouraging people to decide who their chosen supports will be and who will be involved in their care. 	<p>What are the benefits?</p> <ul style="list-style-type: none"> Better health outcomes and improved health literacy Self-determination and choice will improve an individual's quality of life. Recognizes culture and identity as important aspects of wellbeing. Development of more co-operative treatment and care planning that consumer and their whanau are comfortable to adhere to. Person centered care is ensured. 	<p>Common barriers</p> <ul style="list-style-type: none"> Health workers do not understand or value consumer participation in direct care. Information supporting participation is presented at the wrong level of detail (too much or too little) and depth (too simplistic or too complicated). Providing education can be seen as manipulation or influencing decisions rather than true participation. Staff are often not trained in how to elicit critical feedback from consumers. Gathering feedback could be viewed as resource intensive. Consumers may have limited access to resources for establishment of self-help alternatives and collaborative groups. 	<p>How to overcome barriers and facilitate effective Consumer Participation</p> <ul style="list-style-type: none"> Understand and value consumer participation and develop a service delivery culture and norms based on these values. Provide information that supports participation at the right level of detail and depth, check understanding and provide written or audio-visual material to support learning. Encourage consumers to participate in decisions regarding their care and ensure their views are listened to and respected. Investing in training aimed at strengthening the therapeutic alliance and improving consumer participation and feedback. Increase consumer access to resources for establishment of self-help alternatives and support groups.
<p style="text-align: center;">SERVICE DELIVERY & DESIGN</p>	<p>What does this mean?</p> <ul style="list-style-type: none"> Using co-design with consumers in all quality improvement and service design initiatives Involvement in staff recruitment, orientation, and selection processes Resourcing and supporting all staff to make the cultural shift to value consumer engagement. Invest in staff training in skills such as active listening, mutual respect, and particular skills required to actively partner with consumers to elicit feedback. Co-facilitating education and training People with lived experience contribute to development of tools and resources. 	<p>What are the benefits?</p> <ul style="list-style-type: none"> Diminished costs of service operation, by 'getting it right first time.' Staff retention and a staff culture that moves towards having a growth mindset. Provides health information that is user-friendly and understandable. Participation by consumers in mental health service delivery and design is empowering to both the individuals and the organizations involved. Ensures that services are designed and delivered to meet the needs of service users. 	<p>Common barriers</p> <ul style="list-style-type: none"> Staff may struggle to shift beyond the traditional 'carer/client' relationship. For consumers, barriers can include lack of self-confidence, unfair expectations, and mistrust of professionals or the consumer participation process. Limitations in providing remuneration (monetary or otherwise) for time and skill nor cover for expenses such as transport. Medical, legal, and business jargon used by providers may be incomprehensible and alienating to consumers. Lack of sufficient protection and support for consumers and their whānau (family) when they are participating in service improvement projects at the same service where they receive treatment. Processes of participation are seen to be more time consuming than current approaches. 	<p>How to overcome barriers and facilitate effective Consumer Participation</p> <ul style="list-style-type: none"> Treat consumers as equals and experts in respect of their experience and perspective and validate and respect their views. Invite consumers to participate in discussions that lead to real and meaningful decisions about how services are designed and delivered. Create support structures such as consumer forums and advocacy groups, with mandate to implement projects. Create a remuneration process including reimbursement for personal expenses such as transport. Ensure that language used is consumer friendly and that there is minimal use of specialist terms and acronyms, or they are clearly explained. Empower consumer representatives to translate bad experiences into policy proposals for better access, information, choice, advocacy, equity, safety, or redress.
<p style="text-align: center;">GOVERNANCE, STRATEGY AND POLICY DEVELOPMENT</p>	<p>What does this mean?</p> <ul style="list-style-type: none"> Inclusion in policy and procedure development Changing policies to reflect person-centred values. Creating a person-centred vision statement for the organisation – when the values of the organisation are person-centred, then consumer engagement is valued. Consumer representation at senior leadership level Developing a vision of consumer engagement for the whole organisation 	<p>What are the benefits?</p> <ul style="list-style-type: none"> Ensures more accessible services. Improves attitudes towards consumer involvement at all levels of service delivery as it is engrained in the policies and structures of the organisation. Resources can be better targeted if services reflect the needs of the consumers. Representation is equitable and covers a broader understanding of health care and the wider determinants of health. 	<p>Common barriers</p> <ul style="list-style-type: none"> Lack of understanding of how consumers affect the health care system through these different involvement mechanisms. Perception that consumers do not have sufficient knowledge or credentials regarding health care and policy options. Lack of time and payment for consumer involvement. Lack of procedures on how to select and integrate consumers into health policy decision making. Most organisations lack measures to demonstrate the benefit or outcomes of consumer participation. 	<p>How to overcome barriers and facilitate effective Consumer Participation</p> <ul style="list-style-type: none"> Provide opportunities for consumers to participate in discussions leading to strategy and policy review or development. Provide service users and whanau with relevant information prior to meetings and discussions. Develop procedures on how to select and integrate consumers into health policy decision making with clear guidelines on how broadly consumer representation should be considered, e.g., gender, age, ethnicity, educational and other groups. Demonstrate a real commitment to participation by building consumer involvement into the existing structures of the organisation. Implement metrics, tools and/or research to measure outcomes of consumer participation

Appendix

Enablers (Strategic documents)

Ngā Kaiwhakaahei

Resources: For more information about Consumer Participation

<p>ENGAGING WITH CONSUMERS A guide for district health boards</p>	<p>This resource is a practical guide to help New Zealand district health boards, and the health and disability services they fund, to engage better with consumers. It covers consumer engagement in the design and delivery of services, as well as the development of policy and governance procedures.</p>
<p>Guide for developing a consumer experience framework (DHB quality and risk managers)</p>	<p>A guide to developing a framework for collecting information from consumers to improve the quality of health and disability services.</p>
<p>He Ara Oranga: Mental Health Inquiry</p>	<p>recommended specific changes to improve New Zealand’s approach to mental health, with a particular focus on equity of access, community confidence in the mental health system and better outcomes, particularly for Māori and other groups with disproportionately poorer outcomes.</p>
<p>Te Ara Tauwhirotaanga - Pathways that lead us to act with kindness</p>	<p>The model of care is named Te Ara Tauwhirotaanga to echo the aspirations of the community that services and systems are designed to “act with kindness”.</p>
<p>Toward Clinical Excellence: A toolkit to develop consumer participation in credentialing</p>	<p>a general resource for those planning to introduce or further develop consumer participation, as well as specific information related to consumer participation in credentialing systems.</p>
<p>Consumer engagement quality and safety marker (QSM) framework</p>	<p>The consumer engagement quality and safety marker (QSM) seeks to answer the question ‘What does successful consumer engagement look like, and (how) does it improve the quality and safety of services?’.</p>
<p>A Guide to Effective Consumer Participation in Mental Health Services</p>	<p>This is a guide for practice within mental health services. Part of the service role is regular consultation with and involvement of consumers in decisions made about the general running of the service</p>