



A BRIEF SUMMARY OF THE DEVELOPMENT OF

TĀKU REO, TĀKU MAURI ORA MY VOICE, MY LIFE

THE CONSUMER SELF-ASSESSED OUTCOMES MEASURE



Te Pou
o Te Whakaaro Nui

The NATIONAL CENTRE of MENTAL HEALTH RESEARCH,
INFORMATION and WORKFORCE DEVELOPMENT

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 **RESEARCH**
TRANSLATING RESEARCH



INTRODUCTION

Development of the consumer self-assessed outcomes measure, Tāku Reo, Tāku Mauri Ora, or My Voice, My Life, was led by Case Consulting and funded by the Ministry of Health. It was part of the New Zealand mental health outcomes initiative. Tāku Reo, Tāku Mauri Ora is a measure that supports tangata whaiora/service user individual reflection and communication. It can inform tāngata whaiora/service users personal decision making and recovery planning.

A previous report summarised¹ the outcomes literature. It reviewed 18 self-assessment outcome measures in use both in New Zealand and elsewhere. The top three measures were subjected to further scrutiny at service user consultation forums nationally. This report concluded the existing self-assessment measures were inadequate and that:

- tangata whaiora/service user input was lacking in the development of previous measures
- some of the domains service users considered important in terms of their mental wellbeing were not considered
- previous outcome measures focused on service development rather than tangata whaiora/service user wellbeing.

The report recommended that:

- the best source of information on what constitutes a good outcome comes from the person who has experienced it
- tangata whaiora/service user input in the development of outcome measures is vital
- effective input would entail tāngata whaiora/service users taking a lead role throughout the process.

Case Consulting formed a research group to develop and test a 36 item tangata whaiora/service user self-assessment measure. The research team comprised Sarah Gordon, Professor Pete Ellis, Carmel Haggerty, Sarah O'Connor, Dr Lynne Pere, Cherie Ratapu Foster, Dr Richard Siegert, and Dr Frank Walkey. They were guided by the tangata whaiora/service user reference group established at the outset of the project. The piloting of the preliminary and revised measures was supported by a number of individuals, tangata whaiora/service user organisations and other non-government organisations (NGOs). Dr Te Kani Kingi of Massey University and Lyneen Allen of Wellington Deaf Mental Health Service also advised on the measure's responsiveness to specific populations. Responsiveness to, and inclusion of, Māori was addressed by ensuring Māori representation in both the research team and reference group. Time and resources for specific Māori consultation and information gathering processes was allocated.

¹ Gordon, S., Ellis, P., Haggerty, C., Pere, L., Platz, G. & McLaren, K. (2004.) *Preliminary Work Towards the Development of a Self-Assessed Measure of Consumer Outcome*. Auckland: Health Research Council of New Zealand. [Download the PDF](#) from the Te Pou website <http://www.tepou.co.nz> (3.05MB).



DEVELOPMENT AND TESTING OF THE MEASURE

The Tāku Reo, Tāku Mauri Ora measure was developed in four phases. In phase one a preliminary measure was developed and piloted. It was based on findings and recommendations from the 2004 summary of the literature and measures.¹ In phase two, the pilot data was analysed and the preliminary measure was refined. In phase three the revised measure was tested with service users at Capital and Coast Health, Te Roopu Whakapakari and Wellink. In the final phase normative data was developed.

The literature review analysed tangata whaiora/service user conceptualisations of mental illness, mental wellbeing and recovery. It identified a number of key domains that tāngata whaiora/service users across various cultures identified as important. These included relationships, day-to-day life, physical health and culture. A preliminary outcome measure was developed during phase one, based on these findings. The measure consisted of 147 questions. These were divided into the 12 domains identified in the 2004 summary report.¹ Researchers responsible for guiding the measure's responsiveness to Māori suggested a separate section for Māori. A five point Likert response scale was used with the anchors 'none of the time', 'a little of the time', 'some of the time', 'most of the time', and 'all of the time'.

The preliminary measure was piloted with 511 self-identified tāngata whaiora/service users. Participants' trialled the measure at hui, conferences and forums and via tangata whaiora/service user organisations, district health boards (DHB) and NGO services. The results identified 11 distinct and relatively independent factors. There was strong support for a separate section for Māori. The participants were broadly representative of the age, gender and ethnicity range of the New Zealand population. Two hundred (40 per cent) of the participants wrote additional comments in the space provided at the end of the preliminary measure. The high rate of feedback resulted in a thematic analysis being undertaken to compliment the results of the psychometric testing.

The pilot results led to the development of a shorter version with 11 domains and 65 questions during phase two. An additional section for Māori was added. This was made up of 14 questions in two domains. The reference group suggested changes. This resulted in changes to a number of questions and the modification of one domain.

In phase three the revised 79 item measure was tested. Participants from an acute inpatient mental health service along with a mainstream service and a kaupapa Māori community service were asked to complete the measure. Participants from the acute inpatient service were invited to complete the measure at weekly intervals for purposes of re-testing. All others were to complete it at monthly intervals. Twenty-nine participants filled in the measure at least once in the acute inpatient setting. Of this group, 14 filled in the measure three times at weekly intervals. The re-testing of the measure through the acute inpatient service produced some promising results. The analysis showed some change in scores (from higher to lower) in the expected direction for all domain and total scores. This indicates possible responsiveness to change, however limited sample size precludes this reaching statistical significance. There was insufficient data collected from the community-based samples across months for any statistical analysis.

Finally, in phase four, differences in relation to sex, ethnicity, age, length of experience and diagnosis were identified and normative data for the measure was developed.



DISCUSSION

This project aimed to develop a psychometrically sound self-assessed tangata whaiora/service user outcome measure for New Zealand. The primary aim of the measure was to facilitate individual reflection at particular points in time. When used over time the tool would reflect changes that had occurred and inform personal development.

The measure was developed from a recovery focused perspective. It was tangata whaiora/service user led. Its development was informed by tāngata whaiora/service users from around the country. In addition a wide range of consumer organisations and NGO stakeholders were consulted during its development. Attention was paid to ensuring the measures' relevance to Māori tangata whaiora by engaging Māori participation and expertise.

The content of the Tāku Reo, Tāku Mauri Ora measure was developed from information about tangata whaiora/service user conceptualisations of mental illness, wellbeing and recovery. These formed the hypothesised domains of the preliminary measure. The researchers concluded these domains were supported by the subsequent analysis of the preliminary and revised measures.

The tool developers have now completed development and testing of Tāku Reo, Tāku Mauri Ora. The goal was to produce a brief 36 item validated consumer self-assessed outcome measure for use in routine mental health settings. However, validation of Tāku Reo, Tāku Mauri Ora as a measure of change still needs to be completed. Testing in the inpatient setting indicated the measure has some potential as a measure of change, but the sample was too small to confirm this. The measure would require further validation work before consideration for inclusion as part of the national suite of outcome measures.

RECOMMENDATIONS FOR USE OF TĀKU REO, TĀKU MAURI ORA

- Tāku Reo, Tāku Mauri Ora can be used as a self-assessed tangata whaiora/service user outcome measure, with the understanding that validation still needs to be completed.
- The measure can be used for personal reflection. It can assist with tangata whaiora/service user personal recovery. It can also assist conversations between tangata whaiora, their family and mental health service workers.
- Use of Tāku Reo, Tāku Mauri Ora is voluntary. New Zealand tāngata whaiora/service users can use it.
- Tāngata whaiora/service users should have control and ownership of the information and process associated with the measure.



IF YOU ARE INTERESTED IN MORE INFORMATION ABOUT THE MEASURE

There are potential challenges to using this measure in practice. These include the length of the measure and the need to test its use in community mental health settings.

The measure is available for download from Te Pou's website, www.tepou.co.nz. Te Pou may pilot the measure in a community-based mental health service as a tool to assist tangata whaiora/service user personal reflection.

Te Pou is keen to hear about the experiences of any service using the tool.

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For the most up to date information on this project please visit www.tepou.co.nz



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