Key Learning:

Phase 1: Choosing an Outcome Measure

At the outset of the Toka Tū project it was proposed, subject to the project leadership group's endorsement, that one outcome measure would be used to assess the outcomes of the peer-support services participating in this project. The measure proposed was *Taku Reo, Taku Mauri Ora* – My Life, My Voice.

Dr Sarah Gordon (expert advisor to the Toka Tū project) had just completed a PhD thesis which involved the development of this new consumer self-assessed measure of recovery for use in mental health services in New Zealand. The project, which oversaw the development of the measure, was consumer-led and focused and involved over 500 mental health consumers in the pilot phase.

Further information about the development of this tool can be found at:

http://www.tepou.co.nz/library/tepou/taku-reo-taku-mauri-ora-tool

For a copy of the tool:

http://www.tokatu.org.nz/tokatu/pdf/Taku-Reo-Taku-Mauri-Ora-Outcome-Measure.pdf

Toka Tū uses a participatory approach with each stage informed by the other. During the project set-up phase it was clear that a change to our project plan was needed. The reasons for the change included the diversity of the services and the need to gain ethics approval in order to secure the funding.

Diversity of Services

Our first key learning was the diversity in which peer support is delivered.

Within this project, peer support is being delivered in a variety of ways including one-on-one telephone support, within groups, as structured and unstructured programmes, as well as a residential crisis service.

Peer support is delivered by diverse organisations in terms of their size and capacity. Some are very small employing 1–3 paid workers. Others are much larger employing up to 16 staff. Some are stand-alone as part of a Trust , others are a service operating within a much larger organisation which may or may not be consumer-led.

Securing ethics approval

It was also proving difficult to secure multi-regional ethics approval for the collection of individual outcome data to be forwarded to a centralised site. We submitted three applications, the first application was declined because we had not formed the leadership group to define the parameters of the study. The second application was deferred as we needed to obtain Māori consultation from all 10 sites, make changes to the consent form, and seek expert advice on the design of the study.

Our agreement with the Lotteries Grant Board was conditional on Health and Disability (H&D) Ethics Committee approval being granted. Without ethics approval funding was not possible however we needed funding to get ethics approval.

We had a catch twenty-two situation. Lotteries finally agreed to release $10,000.

Another key learning is that while ethics approval is sought and required for one part of the project (collection of individual information) the progress of the overall project was stalled. Getting started proved to be challenging.

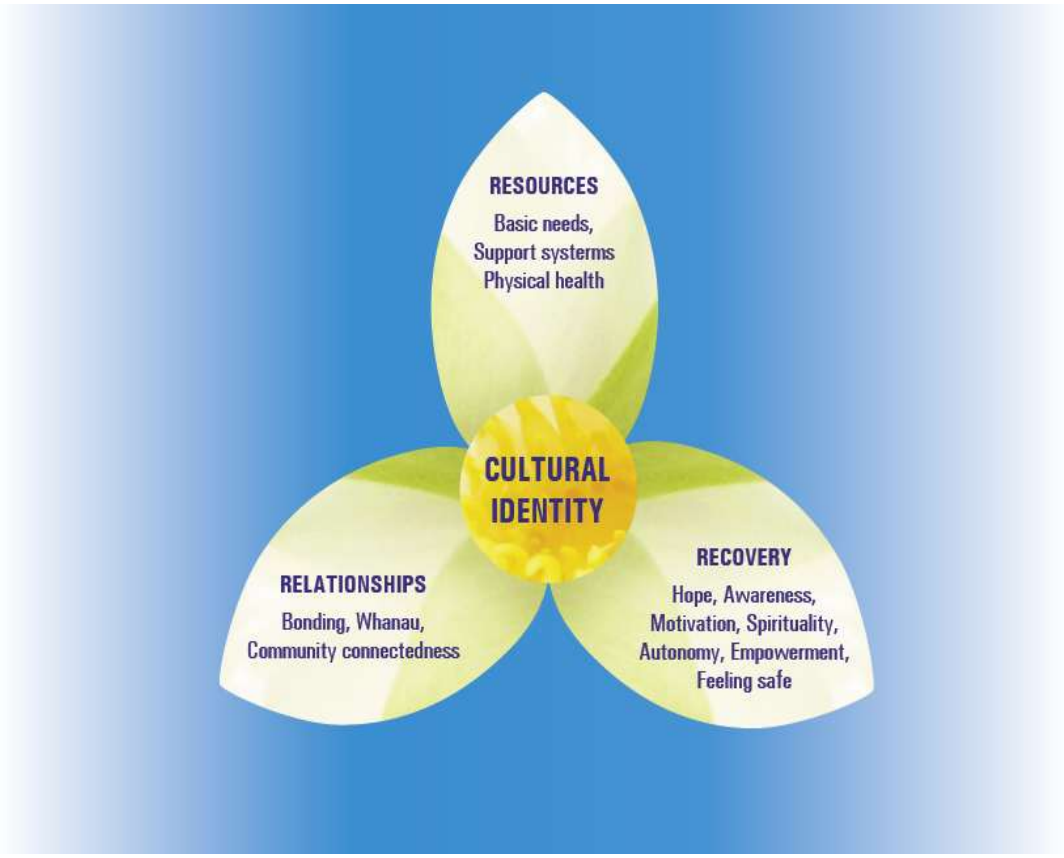
We believe our participatory and developmental approach was in conflict with the way in which the H&D Ethics Committee operated. The Committee application process required the study to be fully predetermined, including specific detail regarding the outcome tools that would be used, and how.

In consultation with the leadership group we decided to change our approach.

Changed approach

We decided to revise our methodology and undertake outcome evaluation by using a range of outcome measures. Participating organisations would be supported to identify and/or develop the resources and procedures necessary to collect, analyse, and report outcome measurement data at a local level. This approach did not require ethics approval, as each organisation collects information for their own service and personal information is not shared outside the organisation. We sought ethics approval for the face-to-face engagement with peers at each participating site.

Each participating peer support service was then required to decide upon an outcome measure to use within their service. The leadership group developed criteria of valued outcomes to consumers, presented in the following diagram:



Identifying the preferred measures

The project team reviewed and produced a summary of 20 potential measures, including those already in use by participating organisations. The number of measures available was overwhelming so the criteria were useful.

The measures were reviewed against criteria including feasibility, in use in New Zealand, length of time to administer, face validity, who was involved in its development, and if it is self-assessed or rated by another person. The leadership group then reviewed each measure and selected the following preferred measures:

- Hua Oranga
- Taku Reo Taku Mauri Ora
- The Human Given's (adapted)
- Warick Endinburgh Scale
- Planning for Outcomes (Wellink Trust)
- WHOQOL
- CDOI

During this phase it became clear there was no one perfect measure.

Choosing a measure

Each participating organisation then chose a measure. The rationale for their choice included:

- acceptability for consumer completion, including those who experience addiction,
- usefulness to the peer and their worker,
- cultural appropriateness, and
- if it measured outcomes, and therefore supported this project.

The length of the tool impacted on choice. Lengthy tools were deemed too long to administer in already time-constrained settings and there was a strong feeling consumers would be put off by the number of questions. The preference was for tools that were short in length and easy to administer.

Language featured highly in terms of acceptability of the measures. Participants wanted to use measures that supported peer support principles of mutuality and reciprocity and were void of power and control references. Strengths-based rather than deficit-focused, and the literacy of participants and the appropriateness of tools for people who experienced addiction problems were all deciding factors.

Use of outcome measures within the NGO sector is beginning to develop momentum and one measure was valued over others because it was already in use. The advantages of a measure already being used is that others have learnt much during their implementation of it, they have developed data capturing systems and regular forums are held to discuss its use. The possibility of being able to compare results was attractive in an environment that is seeking evidence of outcomes and value added.

The measures chosen for use within the Toka Tū project are:

- Taku Reo Taku Mauri Ora
- The Human Givens (adapted)
- CDOI (ORS and RRS)
- WHOQOL-NZ Bref.