

# “Front-load” your co-design—evidence in mental health supports it

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## ABSTRACT

Co-design in quality improvement projects is well-established as an effective way of creating more consumer-centred, whānau-centred care, and to shape solutions that work for consumers as well as services. However, in practice, consumers of health services, families and whānau are often consulted after key decisions about project design are made. This can result in tokenism, missed opportunities for improvement and breached obligations to the Māori right to autonomy, self-determination and control of their own destiny as expressed in Article 2 of Te Tiriti o Waitangi.

“Front-loaded” co-design was used in selection of project areas and project design in Te Tāhū Hauora – New Zealand Health Quality & Safety Commission’s mental health quality improvement work and has been critical to success. With broad sector consultation, one area mental health consumers agreed was a priority for improvement was elimination of seclusion in mental health services, particularly for Māori who experienced significant health inequity in this area. This aim was considered unachievable by many in the sector at the time. However, the zero seclusion project has successfully contributed to reductions in rates of seclusion of all ethnicities, and continues to do so.

“Front-loaded” co-design with Māori and consumer guidance is critical to this success. Furthermore, true co-design also ensures the mana motuhake and tino rangatiratanga (self-determination and control over one’s own destiny) of Māori, and of all peoples who use our health services.

Co-design in quality improvement projects is well-established as an effective way of creating more consumer-centred, whānau-centred care.<sup>1,2</sup> However, co-design in quality improvement often involves consumers of health services, families and whānau *after* key decisions about the project design are made. Such key decisions can include the definition of the problem itself that the project is trying to solve.

## Tokenism, missed opportunities and breaching Te Tiriti o Waitangi obligations

“Front-loading” of co-design, or bringing consumer engagement in early into problem and project definition, is, unfortunately, not common. Experienced commentators suggest early consumer engagement is important,<sup>1,3</sup> but does not always occur. Consumer engagement can often be tokenistic, “*more about legitimizing managerial or professional decisions that would have been made anyway.*”<sup>4,5</sup> In three major co-design projects (lung cancer, kidney and aneurysm), the authors identify early involvement of consumers as a key feature of effective co-designed quality improvement.<sup>4</sup> The power of the consumer voice lies in it being “a

*technology of persuasion*” and means of influencing opinion and debate with clinicians, enhancing project credibility, challenging clinical assumptions and resolving contestation over the appropriateness of proposed changes.<sup>4</sup> As one quality improvement team member concisely articulated:

*“They’re very powerful advocates ... They have a moral stature that you can’t really question. If a patient tells you that the service feels a certain way, you can’t really argue that it doesn’t, because that’s their experience.”<sup>4</sup>*

Starting late with consumers misses major opportunities. Not only can projects fail to properly diagnose and address the problems at hand for those most affected by them, but also in an Aotearoa New Zealand context such an approach actively impinges on the tino rangatiratanga of Māori affected by the problem—Māori right to autonomy, self-determination and control of their own destiny as expressed in Article 2 of Te Tiriti o Waitangi.<sup>6</sup>

Furthermore, leaving consumers out of project definition and design impinges on the self-determination of *all* those directly affected. Early

consumer involvement can both legitimise projects and shape more appropriate responses. Such true co-design is also more creative down the line: a wider range of potential interventions are made available.

### **What is the problem in mental health (and who decides)?**

Extensive evidence and expert consensus recognises that access to, experience, processes and outcomes of healthcare are inequitable for Māori.<sup>7</sup> Specifically, mental illness and how we treat it is also inequitable. The prevalence of mental illness and addiction is one in five for all Aotearoa New Zealanders, but nearly one in three for Māori.<sup>8</sup> In 2017, 41% of adults who experienced potentially harmful seclusion in mental health facilities were Māori, despite Māori representing 17% of the population.<sup>9</sup> To address these inequities and respect the tino rangatiratanga and mana motuhake of those affected, it is critical that Māori affected by improvement projects be engaged early and strongly in co-design. Only this way can improved services be designed that work well for all—and particularly those most affected. Māori want this: a 2024 report from Te Hīringa Mahara—the New Zealand Mental Health and Wellbeing Commission, drawing on the perspectives of “over 300 people with lived experience of mental distress, substance harm, gambling harm, or addiction and whānau, family, and supporters of people with these experiences” found conclusively that “Māori and whānau want to be actively involved in decision-making and the design and delivery of their care.”<sup>10</sup>

### **Te Tāhū Hauora – New Zealand Health Quality & Safety Commission and mental health and addiction quality improvement**

Aotearoa New Zealand’s national quality improvement agency, Te Tāhū Hauora – New Zealand Health Quality & Safety Commission, leads work nationally to improve quality and safety across the health and disability system. We have a focus on quality improvement in mental health services, and true co-design was front-loaded into the national mental health and addiction quality improvement programme from the outset. Consumers were engaged and consulted to decide the programme’s five priority areas of

work. With consumer guidance, these focus areas were established:

- zero seclusion: safety and dignity for all
- connecting care: improving service transitions
- learning from adverse events and consumer, family and whānau experience
- maximising physical health
- improving medication management and prescribing.<sup>11</sup>

Front-loading consumer engagement in problem definition, project design and selection of interventions has borne fruit in the zero seclusion project in particular, which we discuss next.

### **Evidence from quality improvement in seclusion**

Seclusion is defined by Aotearoa New Zealand’s *Ngā paerewa Health and Disability services standard 2021* as “restraint where a person is placed alone in a room or area, at any time and for any duration, from which they cannot freely exit.”<sup>12</sup> The inequitable use of seclusion in consumers of mental health services, harmful to consumers and to carers alike,<sup>13–15</sup> has been rife in Aotearoa New Zealand<sup>16–18</sup> and Australia.<sup>19–21</sup>

Yet, use of seclusion is not inevitable, nor necessarily bound to happen due to services being under financial and staffing strains. The zero seclusion priority area is an ongoing nationwide quality improvement project designed to minimise such harmful seclusion practices, and recent findings have suggested the efficacy of true co-design in this area, particularly for Māori. Early peer-reviewed findings from the authors of this viewpoint now show this work, including development of a cultural/clinical “kete” (basket) of interventions co-designed in a bi-cultural partnership between consumers and cultural and clinical experts, contributed to a statistically significant 22% reduction in the “equity gap” between Māori and non-Māori/non-Pacific peoples in mean monthly rate of seclusion by September 2022.<sup>22</sup> This reduction in seclusion of Māori was sustained through volatile demand for services and myriad other forms of disruption in the first 2 years of the COVID-19 pandemic to September 2022, the period covered by the study. Data collected internally by the programme suggest these reductions have continued, and will be published in the peer-reviewed literature in due course.

Drawing on Māori governance, leadership, insight and lived expertise in the experience of and approaches to reduction of seclusion was critical to this good result for Māori.

## What effective, inclusive co-design can look like—one approach

Across all areas of our mental health and addiction quality improvement programme work, comprehensive, culturally informed co-design processes are emphasised to involve, engage and learn from Māori lived experience from the outset.

### Governance

In practice, this means governance of priority areas of work is guided and informed by Māori representation: the small national team includes clinical, cultural and consumer leadership with a senior Māori kaumātua (a respected tribal elder in a Māori community who has been involved with their whānau for many years), quality improvement specialists and data experts. The programme is supported by both a Māori advisory group and a consumer advisory group. A cross-sector leadership group maintains oversight of the programme and advises the programme team.

### Design

True co-design should be co-creative, participatory and open, and should directly involve consumers, family and whānau in designing the solutions as well as prioritising the work. Māori and other consumers were engaged in workshops for all five project priority areas, by sharing consumer and whānau stories, in active-participation learning sessions and in project teams in each of the 20 districts in Aotearoa New Zealand's health system (as it was then configured). Māori worldviews and knowledge systems were and continue to be explicitly considered within any co-design process.<sup>23</sup> The consensual approach itself is congruent with the traditional Māori practice of wānanga (open discussion where a group attempts to gain a deeper understanding of an issue). Wānanga brings people together in an open forum explicitly to ensure that many perspectives and solutions are reflected in discussions and solutions. In this way, a bi-cultural (and cultural/clinical) mode of working and partnership was created from the outset of the work and built into the governance of the programme.

### Testing of interventions

Our quality improvement approaches align with the Institute for Healthcare Improvement's collaborative breakthrough series methodology.<sup>24</sup> This methodology provides a structure for organisations to collaborate on the selection, testing and implementation of change in specific clinical areas where current practice deviates from best scientific knowledge, improved results would improve quality of care and the possibility of improvement has been demonstrated by at least some sentinel organisations.<sup>24</sup> The methodology has shown powerful improvement overseas<sup>25,26</sup> and in Aotearoa New Zealand.<sup>27,28</sup>

This methodology typically uses improvement science to test evidence-based interventions locally, measure the impact of these changes and—if successful—support other services to implement the changes more widely. However, with much of our work, no pre-existing “bundle” of evidence-based practices was known.

So, a “formative collaborative approach”<sup>29,30</sup> was taken, where harm areas and potential interventions are investigated and established as part of the project. The project teams from across the country were tasked with first applying the co-design knowledge gained from workshops to their own environment. Here, teams are encouraged to understand where opportunities for improvement exist within their systems, to develop and share ideas and test them, contributing to the development of a locally relevant change package informed by Māori lived experience.

Teams then applied quality improvement learning in rapid-cycle tests of change to test, modify and scale-up ideas for change, with a dedicated bespoke measurement framework, including measures of inequity.

### Conclusion

The programme uses this partnership between clinical and quality improvement expertise and the expertise in the lived experience of consumers and Māori in both co-design and the formative collaborative. A bicultural partnership of this kind enables consumers and Māori to lead design and delivery of care in their own communities. It requires effective engagement by clinicians and staff with quality improvement expertise with those with lived experience, genuine mutual trust and respect, and the sharing of ideas, values, beliefs and models of wellness.

It is our belief that, through these approaches,

clinical options for improvement are made more acceptable to Māori and can be delivered through Kaupapa Māori health services. This truer form of co-design enables a broader range of options or choices to be tested, developed and scaled and then—ultimately—accepted by the people for whom they are supposed to work.

True co-design is not easy. Early involvement of consumers may well challenge initial assumptions and ultimately shift the direction of the work

from what was originally anticipated. However, the rewards are worth it. True co-design ensures projects are credible and legitimate, and ultimately shapes solutions that work for consumers as well as for the services themselves—the true definition of a successful project outcome. Furthermore, true co-design also ensures the mana motuhake and tino rangatiratanga of Māori, and indeed the self-determination that all peoples who use our health services deserve.

**COMPETING INTERESTS**

There are no competing interests to declare.

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