Adjusting protocols in clinical research: finding the point of cultural/clinical fusion

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The Hauora Manawa/Heart Health: Community Heart Study is a research project currently being undertaken at the University of Otago, Christchurch. The purpose of this study is to identify the prevalence of cardiovascular risk within three cohorts: a rural Maori (Wairoa, Hawkes Bay), an urban Maori (Christchurch) with an age- and gender-matched non-Maori cohort (Christchurch). Participants (aged 20–64 years) were randomly selected through the electoral roll and invited to take part in a 1.5–2-hour cardiovascular screening clinic (undertaken in Wairoa in 2007, Christchurch in 2008) then to participate in a 20-minute follow-up visit two years later to further measure and monitor any changes to their cardiovascular risk.

This project was undertaken utilising a Kaupapa Maori Research framework to ensure Maori beliefs, values and experiences were central to the research and that the research methods and analysis supported validating Maori realities. Utilising a Health Research Council strategic development grant, the research team undertook a number of consultation hui with iwi (Ngati Kahungunu ki Wairoa Taiwhenua and Mana Whenua ki Waitaha) and Maori health providers (in both Wairoa and Christchurch). The two following clinical/cultural concerns were raised and discussed.

In developing the clinic protocols, the team visited other clinical research projects and clinical centres. Through this process two potential conflicts were identified between tikanga (Maori cultural protocols) and current clinical practice. The first was the lack of modesty for participants when an ECG or echocardiogram was being performed and the second was the use of a pillow supporting the arm during venepuncture procedures.

In this study, because participants were randomly selected and were participating for altruistic reasons, the team relied on their goodwill and enjoyment of the experience to engage with the research. If the study design did not acknowledge cultural incongruence within the design, and therefore amend the design, there was a likelihood participants would withdraw from the study, not enjoy the research experience but not report their concern or, thirdly, tell other potential participants that the experience was unpleasant. The first conflict we identified was that a patient was required to be bare-chested while having an electrocardiograph (ECG) and/or an echocardiogram.

Therefore the research team, in collaboration with a community member* decided to design and develop specific participant gowns that would allow a high degree of modesty for participants but also allow clinicians to undertake the required tests. Three designs were developed before the final gown was accepted by stakeholders and clinicians. The gowns were designed in three sizes all generously proportioned to allow

* The community member had been a previous cardiac patient and had experienced several ECG and echocardiograms during her time in that service.
clinicians adequate space to perform procedures, while also ensuring participants’ comfort.

The second issue involved using bed pillows (with white pillow cases) to support the arm while participants were seated to have their blood taken. A number of other clinical solutions were discussed with clinic teams, but they felt because they were not aware of any reports of Maori patients feeling uncomfortable with these processes, it was not necessary to change procedures within their clinical practice.

However, all stakeholders agreed that the lack of addressing these two issues would lead to lower engagement with the project, but more importantly would not align this project with the true intention of Kaupapa Maori based research.

In response to the use of pillows for blood taking, specific arm chairs were purchased which had high arm rests, which were covered with a disposable protective sheet. Bright-coloured, ‘Cuddle Buddies’ cushions were also purchased to use as support when required, which were also covered by a disposable protective sheet. This was accepted as appropriate by stakeholders and clinicians.

During the screening clinics, participants in both Wairoa and Christchurch commented on their high satisfaction with being offered the gown. Participants commented that it wasn’t just about their bare chests but also that the gowns covered their stomachs, allowing them to maintain a level of dignity during the procedure. Although it was originally anticipated that the gowns would be utilised mainly by women, many men also took up the option to wear them.

The gown made me feel I was respected, that it was about me. (Female participant)

I didn’t want that pretty girl [the echosonographer] to see my puku, so it made me feel good. (Male participant)

I liked that my mana was kept intact throughout the procedures—that I didn’t have to get naked. (Male participant)

Study participants commented positively on the gown being normalised by the clinicians and that they were ‘a good size.’ Clinicians reported that it took a ‘few goes’ to get used to the gowns, but they soon adapted and the gowns worked well for them, especially after they could see the participants’ level of comfort. Participants also reported feeling comfortable with the blood taking procedure, noting that it was done in a way they felt was culturally appropriate.

Although two-thirds of the research cohort were Maori and the clinical protocols were tailored to ensure their participation and acceptance of the research, it is interesting to note that non-Maori participants also reported an appreciation of the use of the clinical gowns.

In conclusion, the following lessons were noted:
1. That the research team identified that the framework of Kaupapa Maori Research enabled them to critique and challenge current clinical research protocols.
2. That in working alongside Maori community stakeholders allowed the development of solutions, which enabled a fusion between clinical and cultural practice.
3. That changes to clinical protocols to match Maori cultural expectations, can also result in higher levels of satisfaction for non-Maori participants’ experience within clinical research procedures.