

Māori health state preferences: a pilot study*

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Abstract

Objective: To pilot research of potential differences between Māori and non-Māori in their health state preferences and to investigate the adequacy of a standard valuation instrument's — the EQ-5D's — representation of 'health'.

Methods: Health state valuations and perceptions of the EQ-5D's adequacy were collected in 2000 via a self-completed but interviewer-assisted questionnaire from 66 Māori in New Zealand accessed through cultural networks; five participants also undertook in-depth post-questionnaire interviews. Their valuations and perceptions were compared with non-Māori and Māori respectively from an earlier survey that used an electoral roll sampling frame.

Results: The valuations were not statistically different to valuations from the non-Māori and Māori electoral roll samples, although the majority of respondents failed to score the health 'state' dead. Participants exhibited more pairwise inconsistencies than their electoral roll counterparts and most considered the EQ-5D's representation of 'health' to be adequate, although other aspects not included in the instrument were also important.

Conclusions: The hypothesis of differences between Māori and non-Māori in their health state preferences is not supported. Nor is there evidence that the EQ-5D fails to capture what Māori perceive as 'health' any more than it does for non-Māori, although the high prevalence of missing values for dead is worrisome.

Implications: These tentative findings suggest no fundamental rationale for differentiating between Māori and non-Māori when using the EQ-5D to represent (generic) health outcomes or to value them for economic evaluations.

Introduction

Cost-utility analysis (CUA) has been used to inform the spending decisions of New Zealand's purchasers of publicly-funded health care, the Pharmaceutical Management Agency (PHARMAC) and the recently disestablished Health Funding Authority (HFA).^{1,2} Central to CUA are Quality Adjusted Life Years (QALYs), which combine length of life with a measure of health-related quality of life, the latter usually based on the health state valuations of the general public (as both taxpayers and potential patients).

A recent National Health Committee report recommended that the extent of any differences between Māori (14.5% of the population³) and non-Māori in their health state valuations be investigated, as well as the validity and relevance to Māori of the instrument used for this purpose, particularly the representation of 'health'.⁴ The basis for these concerns is the *whare tapa wha* ('four-sided house') model of Māori health, which augments *taha tinana* (biological health — the typical Westernised view) with *taha hinengaro* (the mental side), *taha wairua* (the spiritual side) and *taha whanau* (family well-being) — all four 'sides' of the 'house' are necessary for its symmetry and strength.⁵

Such differences between Māori and non-Māori, were they to exist, would have important policy implications for CUA in New Zealand, particularly with respect to prioritising services for Māori. It is also widely recognised in New Zealand that the health and disability support needs of Māori will be better served by a system with active Māori involvement in its design and management.⁶

Previous international research has found little or no difference between ethnic groups in their health state valuations,^{7,8} and a local survey by Devlin et al. (2000)⁹ from which a New

Zealand ‘tariff’ of health state preferences was generated may suffer from sampling frame bias (explained below). Thus, the present paper reports the findings of a pilot study of Māori health state valuations using the EuroQol Group’s EQ-5D, which are compared with non-Māori and Māori valuations respectively from Devlin et al.’s study. As well, Māori perceptions of the instrument and the tendency for the health ‘state’ dead to not be valued and the extent of ‘logical inconsistencies’ are compared.

Methods

The EQ-5D health state classification system and questionnaire

The EQ-5D, a leading generic health state classification system internationally¹⁰ (and the one used by PHARMAC²), describes health states according to five dimensions: the degree of mobility, ability to undertake self care, ability to participate in usual activities, degree of pain/discomfort and degree of anxiety/depression. (Note that compared to the *whare tapa wha* model of Māori health outlined in the previous section these dimensions are mostly biological in nature.) Each dimension has three levels: (1) no problems, (2) some problems, (3) extreme problems. With the health ‘states’ unconscious and dead, 245 states result from all possible combinations of these three levels across the five dimensions — each codifiable with a five-digit number corresponding to the five dimensions in the order listed above. More information on the EQ-5D is available from the EuroQol Group’s web-site <<http://www.euroqol.org>>.

Study participants were asked in a questionnaire to score the EuroQol ‘common core’¹¹ of 15 hypothetical health states, including 11111 (i.e., no problems on all dimensions) and dead, using a visual analogue scale (VAS) ranging from “worst imaginable health state” (a score of 0) to “best imaginable health state” (a score of 100). Valuations for 11111 and dead are

essential for rescaling each participant's valuations so that 11111 = one and dead = zero (negative values are interpretable as belonging to states considered to be worse than dead). Participants were also asked "Do you feel that the way of describing 'health' used in this questionnaire covers all the aspects of health that are important to you?"; and "If you ticked 'no', please tell us what other aspects of health are important to you?"

After consultation with the HFA's Māori Health Group, the standard EQ-5D questionnaire (also used by Devlin et al.⁹) was adapted to probe issues such as participant's *iwi* (tribe, people) affiliation and ability in *te reo* (Māori language). These characteristics were deemed to be indicators of the strength of participant's Māori cultural affiliation. The questionnaire is available on request from the authors. Although self-completed by participants, the questionnaire was administered in face-to-face interviews, thereby allowing the interviewer (the paper's first author) to respond to participants' questions and gain insights into the difficulties experienced completing the questionnaire. Ethical approval was obtained from the University of Otago Ethics Committee.

The sample

Devlin et al.'s study (the comparator to the present survey) used a self-completed questionnaire posted in 1999 to 3000 adult New Zealanders randomly selected from the electoral roll.⁹ Māori were under-represented in their 1360 responses, which may in part be explained by sampling frame (the electoral roll) bias if Māori are less likely to be registered to vote or their permanent address details are not up-to-date (e.g., because of migration for seasonal work). The Māori electoral roll as an alternative sampling frame may be unrepresentative of Māori because these electorates are usually won by Labour Party candidates and therefore (given the winners are decided on a 'first-past-the-post' basis) Māori who do not support Labour would be less inclined to register on that roll. These issues, in

part, form the rationale for the present study, in that sampling methods based on established networks of Māori and a ‘personal approach’ may be a more appropriate manner of accessing Māori.

Accordingly, selected leaders in several Māori communities in New Zealand were asked for their help in recruiting study participants (over the age of 14), resulting in three groups completing the questionnaire in 2000: (i) 27 people involved with Te Roopu Awhina, a home visit service in Wellington, accessed through HFA Māori Health Group networks; (ii) 12 people at a *hui* (gathering) for Tainui people in Dunedin, accessed through University of Otago networks; and (iii) 25 people involved with Te Wananga O Raukawa, a Māori tertiary institute in Wellington, accessed through a Māori academic. Another two people were recruited through the Ngai Tahu Māori Health Research Unit, bringing to 66 the total number of participants. After completing the questionnaire, five people were interviewed in-depth concerning their perception of the questions and ‘how’ they went about answering them.

The mean valuations of these 66 individuals were compared with the means of the 344 non-Māori and 29 Māori respectively in Devlin et al.’s study (hereafter known as ‘electoral roll non-Māori’ and ‘electoral roll Māori’) who scored the same 15 ‘common core’ EQ-5D health states. (Devlin et al.’s questionnaire had three versions with different sets of health states for the purpose of estimating via regression analysis a full tariff of 245 EQ-5D health state values). The logical consistency of participants’ valuations was also checked. Valuations are deemed logically inconsistent if an unambiguously *less* severe state is given a *lower* score than a more severe one. For instance, 11111 ‘ought’ (logically) not to be valued below 21111 — otherwise the respondent is implying that she/he would prefer moderate immobility (i.e., level 2) over full mobility (level 1). A maximum of 52 pairwise inconsistencies are possible

amongst the 15 health states surveyed, although individuals with missing data are exposed to fewer potential inconsistencies.

Results

The 66 Māori surveyed tended to be younger (an average age of 41) and more likely to be students than their counterparts in the electoral roll non-Māori and Māori samples, but older than the New Zealand-resident Māori population over 15 years of age.¹² Half were females. 52 (79%) could at least understand spoken Māori and 61 (92%) attended functions on a *marae* (tribal gathering place) at least once a year, with 47 (71%) attending at least six times a year. 29 (44%) did not identify themselves with any ethnic group other than Māori. Characteristics of the electoral roll Māori in these regards are not available for comparison.

50 (76%) participants reported that the EQ-5D's representation of health was adequate, compared with 67% and 74% of the electoral roll non-Māori and Māori (these differences are not statistically significantly different at the 5% level). Of the extra dimensions suggested by participants as being important, many focused on aspects of health *care* (such as diet and exercise) rather than health *per se*. Only 8 of the 16 participants who stated there was 'more to health' than as described in the questionnaire made suggestions that could be linked with aspects of the *whare tapa wha* model outlined earlier. Moreover, the view from the five individuals interviewed after completing the questionnaire was that there is no difference between what Māori perceive to be 'health' and what they believe non-Māori perceive it to be. They also generally felt that the questionnaire was challenging and presented "strange concepts to think about".

47 (71%) participants did not score dead in the questionnaire, which is considerably higher than the electoral roll non-Māori (36%) and Māori (28%). Many of the participants also had

problems scoring the other health states on the VAS (e.g., they often asked for guidance as to what was expected of them). It is possible, however, that the people on the electoral roll who were unable/unwilling to value dead (or the other states) did not return the questionnaire they were sent, so that rather than being classified as not having valued dead (as above) they chose not to participate. In the present survey the interviewer observed there to be near-universal neglect to read the questionnaire instructions; the introductory paragraphs were often ignored and participants immediately began completing the first page.

Missing values for dead for these 47 participants presented an immediate problem for further analyses. As mentioned earlier, dead (and 11111) are required for rescaling participants' valuations to common endpoints (zero and unity). Otherwise, their valuations are relative to their idiosyncratic VAS endpoints (as noted earlier), "worst ..." and "best imaginable health states", and therefore comparisons across individuals are problematic. However, rather than discard these responses they are included here, but the rescaled valuations from the 19 participants who did score dead are analysed separately. For this latter group, Table 1 presents the mean rescaled values of the surveyed health states, as well as their electoral roll non-Māori and Māori counterparts. Table 2 presents the unscaled valuations (hence the scores are between 0 and 100 rather than 0 and 1). Two-tailed t-tests (assuming unequal variances) that the means of the electoral roll non-Māori and Māori respectively are not statistically different from the present sample were conducted. None in Table 1 are statistically significantly different (at the 5% level and with no adjustment for multiple comparisons), although five means (on four states) in Table 2 are significant (signified with an asterisk). Also, the valuations of the 29 who identified themselves as solely of Māori ethnicity were not significantly different to the valuations of the 37 Māori who also identified with other ethnic groups (detailed results are not reported here).

Tables 1 and 2 about here

The mean rescaled value for state 11211 being greater than unity (reported in Table 1) is *prima facie* surprising, given 11111 (i.e., full health) = 1 by construction. This is explained by some of the 19 respondents who valued this pair valuing 11211 above 11111. Indeed, of the 66 participants in the present survey, 46 (69%) exhibited at least one logical inconsistency in their valuations, compared to 71% and 60% in the electoral roll Māori and non-Māori samples. Figure 1 shows the proportions for each sample. As can be seen, participants in the present study in general had more pairwise inconsistencies than the electoral roll samples, including their being twice as likely to exhibit seven or more inconsistencies.

Figure 1 about here

Discussion

As noted in the Introduction, this research was intended to be a pilot for a more extensive study. It has enabled the use of non-standard sampling procedures to be explored and the identification of several research design issues that may inform future work. Using Māori networks to access participants overcomes concerns about the bias inherent in formal sampling frames and produced high participation rates (only three people declined to participate). However, such ‘snowball’ or ‘chain’¹³ (non-random) sampling raises other obvious challenges; in particular, future research will need to balance cultural considerations against ensuring that samples are representative of the Māori population. In particular, our sample comprised a greater proportion of students than the electoral roll Māori and non-Māori samples, which is not surprising given the three groups from which we recruited

participants. However given their strong Māori cultural affiliations they might reasonably not be expected to be more ‘Western’-influenced in their thinking than other Māori people.

Tentative conclusions can be drawn that may form the basis for hypotheses to be tested more fully in the future. First, there is no evidence to suggest that the EQ-5D fails to capture what Māori perceive as health any more than it does for non-Māori. Despite models of Māori health portraying more than solely biological well-being there is no evidence that most Māori conform to this view (nor is there evidence that Māori conform to this view more than non-Māori). The sentiment was expressed by those interviewed that the *whare tapa wha* model of health is “just as relevant to non-Māori”.

That the majority of participants failed to score dead on the VAS is a concern because that renders all of their data useless for estimating health state tariffs suitable for CUA. As well as being higher than in Devlin et al.’s study, the proportion is also considerably higher than for other research using the same instrument.¹¹ Why is this so? Were participants unwilling to score dead, perhaps for religious or cultural reasons, or just unaware of the requirement in the questionnaire to do so?

Without further information, the first possibility is moot. With respect to the second possibility, many participants did not read the instructions and therefore may have been unaware of what was being asked of them. The questionnaires used in self-completed valuation exercises are complex and impose a heavy responder burden; indeed, it has been suggested that such exercises may be too complicated for self-completed questionnaires, requiring interviewer-based methods instead.¹⁴ Nonetheless, self-completed questionnaires are widely used and although VAS has several well-known limitations^{15,16,17} it has been shown to be more feasible and reliable (as well as being relatively inexpensive) than ‘trade-

off’ based alternatives such as standard gamble and time trade-off techniques.¹⁵ Another contributing factor may be the lower literacy rates of Māori compared to non-Māori.¹⁸ Further research should supplement preference elicitation with detailed qualitative investigation to resolve these issues.

These concerns may also explain the high rates of logical inconsistencies in participants’ valuations. The rates here and in the Devlin et al. study are higher than those reported for other countries.^{15,19} However direct comparisons are problematic because some studies — but not this one or Devlin et al. — exclude responses that exhibit extreme types of inconsistency, e.g., states more highly valued than 11111.¹⁵

Finally, there is little or no evidence for differences in valuations between Māori and non-Māori — a finding which is in keeping with the international literature on health state valuation by ethnic groups.^{7,8} However, the small sample size, coupled with the lack of rescalable data, resulted in large variances in reported values which may be hiding actual differences. Further, the use of unscaled data is problematic, especially given the large gap in health status between Māori and non-Māori.²⁰ Māori may be more likely to take as their valuation ‘reference points’ the health experience of Māori, rather than the health experience of other New Zealanders, as has been hypothesised for Aboriginal people of Australia.²¹ This revolves around the issue of participants’ interpretation of the VAS endpoints; for example, does “best ...” and “worst imaginable health state” mean for a person like me (i.e., Māori) or the best possible health state for anyone?²²

It is also likely that simple Māori–non-Māori comparisons of the sort focused on in this paper overlook the diversity of Māori as a people.⁵ Previous research reports little difference between non-Māori and young Māori using the SF-36 but that older Māori tend to have a

more traditional view of health.²³ Future research needs a sufficiently large and representative sample such that the heterogeneity of Māori can be explored and so that the effect of potentially confounding influences on health state valuations, including socio-demographics and health status, can be controlled for.

Nevertheless, these findings suggest no fundamental rationale for differentiating between Māori and non-Māori when using the EQ-5D to represent (generic) health outcomes or value them for economic evaluations. There is tentative support for the conclusion that tariffs of health state preferences based on samples of the general public are appropriate for use in prioritising all services, including services targeted at Māori. It may, of course, be appropriate for society to attach higher values to the health benefits arising from certain services or for certain groups, such as on the basis of ethnicity, and weights can be attached to promote these ends. However, this is an ethical issue and (positive) economics cannot make such value judgements.

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Table 1: Mean rescaled valuations for Māori, electoral roll non-Māori and electoral roll Māori — mean value, (standard deviation), *number of responses*.

Health state	Māori	Electoral roll non-Māori	Electoral roll Māori
11211	1.09 (0.79) <i>19</i>	0.84 (0.30) <i>219</i>	0.82 (0.17) <i>19</i>
21232	0.31 (0.41) <i>18</i>	0.30 (0.79) <i>219</i>	0.47 (0.41) <i>20</i>
11122	0.76 (1.09) <i>18</i>	0.51 (0.57) <i>217</i>	0.67 (0.78) <i>20</i>
11121	0.94 (0.95) <i>18</i>	0.73 (0.48) <i>219</i>	0.83 (0.65) <i>20</i>
22233	0.30 (0.35) <i>17</i>	0.10 (1.57) <i>217</i>	0.23 (0.37) <i>19</i>
33333a	0.05 (0.38) <i>19</i>	-0.09 (1.74) <i>218</i>	-0.01 (0.33) <i>20</i>
33321	0.14 (0.27) <i>19</i>	0.06 (1.74) <i>219</i>	0.14 (0.32) <i>20</i>
21111	0.84 (0.50) <i>19</i>	0.75 (1.09) <i>215</i>	0.93 (0.60) <i>20</i>
Unconscious	-0.07 (0.18) <i>19</i>	-0.02 (1.63) <i>212</i>	0.11 (0.35) <i>20</i>
12111	0.65 (0.39) <i>19</i>	0.56 (1.72) <i>215</i>	0.64 (0.24) <i>20</i>
11112	0.83 (0.66) <i>19</i>	0.75 (0.39) <i>216</i>	0.87 (0.69) <i>20</i>
32211	0.23 (0.31) <i>19</i>	0.24 (1.77) <i>212</i>	0.38 (0.32) <i>20</i>
33333b	0.00 (0.31) <i>18</i>	-0.08 (1.76) <i>216</i>	0.00 (0.35) <i>20</i>
22323	0.10 (0.26) <i>17</i>	0.08 (1.62) <i>207</i>	0.25 (0.41) <i>20</i>

Notes: The a and b suffixes denote states for which valuations were sought twice (on separate pages of the questionnaire). For each of the three groups, the sample sizes (italicised) differ for each health state because not all respondents valued that particular state.

Table 2: Mean unscaled valuations for Māori, electoral roll non-Māori and electoral roll Māori — mean value, (standard deviation), *number of responses*.

Health state	Māori	Electoral roll non-Māori	Electoral roll Māori
11211	80.61 (17.65) <i>56</i>	79.73 (18.84) <i>294</i>	78.45 (20.98) <i>22</i>
11111a	83.01 (20.58) <i>54</i>	95.44* (55.36) <i>290</i>	92.29 (17.37) <i>21</i>
21232	45.04 (28.93) <i>52</i>	42.62 (24.66) <i>297</i>	44.59 (27.93) <i>22</i>
11122	56.10 (28.78) <i>52</i>	56.17 (22.57) <i>292</i>	54.43 (21.43) <i>21</i>
11121	75.47 (21.35) <i>53</i>	73.11 (20.36) <i>293</i>	68.68 (20.47) <i>22</i>
22233	39.31 (31.14) <i>49</i>	30.52 (24.80) <i>284</i>	73.68 (208.29) <i>22</i>
33333a	20.67 (29.38) <i>48</i>	15.67 (27.21) <i>281</i>	8.52 (22.81) <i>21</i>
33321	28.70 (31.60) <i>50</i>	26.91 (27.11) <i>286</i>	20.57 (23.37) <i>21</i>
21111	67.52 (26.69) <i>45</i>	82.41* (78.74) <i>290</i>	78.19* (15.31) <i>21</i>
11111b	84.93 (20.70) <i>45</i>	95.57* (55.82) <i>289</i>	89.76 (22.76) <i>21</i>
Unconscious	11.39 (23.62) <i>41</i>	25.08* (88.03) <i>277</i>	16.90 (25.52) <i>21</i>
12111	55.95 (31.56) <i>44</i>	66.69 (60.47) <i>289</i>	60.33 (22.07) <i>21</i>
11112	70.35 (22.22) <i>46</i>	71.30 (21.39) <i>287</i>	71.50 (23.86) <i>22</i>
32211	35.57 (29.57) <i>47</i>	41.82 (25.64) <i>284</i>	39.71 (25.64) <i>21</i>
33333b	19.02 (27.77) <i>45</i>	14.61 (25.69) <i>282</i>	9.10 (22.66) <i>21</i>
22323	28.72 (27.57) <i>43</i>	27.40 (24.42) <i>279</i>	26.52 (19.88) <i>21</i>
Dead	8.05 (12.69) <i>19</i>	8.37 (14.40) <i>220</i>	11.95 (22.85) <i>21</i>

Notes: The a and b suffixes denote states for which valuations were sought twice (on separate pages of the questionnaire). * indicates statistically significant differences at the 5% level. For each of the three groups, the sample sizes (italicised) differ for each health state because not all respondents valued that particular state.

Figure 1: Logical inconsistencies —percentages of sample groups

