# The effect of ethnicity on different ways of expressing cardiovascular treatment benefits and patient decision-making

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# ABSTRACT

**INTRODUCTION:** The way information is presented to communicate risk and treatment benefit affects patients' understanding and perception of their risk and can influence their decisions.

**AIM:** To assess the effect of ethnicity on patient preferences for different ways of expressing risk and treatment benefits.

**METHODS:** Using tailored questionnaires, we surveyed Māori, Pacific and Indian peoples of known CVD risk to assess format preferences encouraging them to take medication or assist their understanding of possible treatment benefits. Statistical analysis determined any association of ethnicity with patient preferences.

**RESULTS:** Of the 376 participants, 50% identified as New Zealand (NZ) European; 15% Māori; 25% Pacific and 10% Indian ethnicity. Patients preferred positive framing of risk (66%). Relative risk was the format reported as most encouraging to take medication and to understand risk, with natural frequencies least preferable, although Pacific people significantly preferred natural frequencies (p<0.0001) compared with other ethnic groups. The majority (55%) preferred pictures to numbers for explaining risk. Māori, Pacific and Indian participants significantly preferred 100-people chart formats over bar graphs compared with NZ Europeans/Others (p=0.002). Most (68%) preferred doctors to give their opinion on taking medication instead of explaining risks using numbers and/or pictures. Pacific and Indian peoples significantly preferred to NZ European/Other and Māori participants (p<0.0001).

**DISCUSSION:** Ethnic differences in patient preferences for communication formats and decision-making should be considered when tailoring effective communication in primary care. However, individual preferences cannot be presumed and a combination of methods should routinely be used.

**KEYWORDS:** Decision making; ethnicity; health communication; patient preference; primary health care; risk assessment

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### Introduction

Although mortality from cardiovascular disease (CVD) has decreased substantially in the last 25 years in New Zealand (NZ),<sup>1</sup> it still remains higher than the corresponding rates in similar developed countries.<sup>1</sup> Large inequalities in risk and outcomes for CVD exist in NZ, reflecting a complex mix of socioeconomic, ethnic and accessrelated factors.<sup>2</sup> The relative burden of CVD falls heaviest on Māori, Pacific and Indian populations and those who live in the most deprived socioeconomic areas.<sup>3,4</sup>

Identification and treatment of individuals at increased risk of CVD is important to prevent or delay future events.<sup>5</sup> Screening based on risk prediction tools provides a relatively inexpensive method of identifying and addressing risk factors.<sup>6,7</sup> New Zealand guidelines recommend general practice CVD risk screening for all men over 45 years, all women over 55 years, and 10 years earlier for high-risk population groups, using paper-based or electronic risk scoring.<sup>8</sup> The derived five-year CVD risk is used as a basis for targeting treatment.<sup>8,9</sup> It has been estimated that, for persons at high risk, evidence-based drug treatment could more than halve the risk of CVD events over the next five years.<sup>10,11</sup>

Various formats are used to communicate risk and treatment benefits. The way information is presented is likely to affect patients' understanding of the evidence, their perception of their risk and, hence, influence their decisions.<sup>12</sup> Some studies have manipulated risks and benefits of treatment expressed in different formats in clinical settings, but there is limited research in this field.<sup>13,14</sup> Conflicting evidence exists about how best to present information to patients.<sup>15-17</sup> Along with other patient characteristics, ethnic differences may require tailoring of how risk is communicated for optimal understanding.

The aim of this study was to assess the effect of ethnicity on patient preferences for different formats of expressing treatment benefits and decision-making.

# Methods

# Sampling frame

A cross-sectional survey of patient preferences was conducted in nine selected general practices in the Auckland region, with a mix of affluent, middle-income and lower-socioeconomic populations, including practices with a high proportion of enrolled high-risk population groups. Ethnicity was self-reported and prioritised in the following order into four ethnic groups: New Zealand European/Other, Māori, Pacific, and Indian peoples. Indian ethnicity was defined in keeping with New Zealand CVD Guidelines8 as peoples from India, Pakistan, Bangladesh, Sri Lanka, Afghanistan, Nepal and Tibet, and henceforth referred to as Indian peoples. General practices were eligible if their practice nurses or general practitioners were conducting formal CVD risk assessments as part of routine care and they agreed to participate. The study received

# WHAT GAP THIS FILLS

What we already know: Various formats are used to communicate risk and treatment benefits. The way information is presented is likely to affect patients' understanding of the evidence, their perception of their risk and hence, influence their decisions.

**What this study adds:** Ethnic differences in patient preferences for communication formats and decision-making should be considered when tailoring effective communication methods in primary care.

ethical approval from the Northern X Regional Ethics Committee (Ref. NTX/06/09/108).

## Study instruments

Questionnaires informed by existing literature were developed and piloted. The information given within each questionnaire data varied according to five-year CVD risk (5-9%, 10-14%, 15-19%, 20-24%, 25-29%, 30-34%). Patients were asked to consider a new medication with few side effects to be taken daily to reduce their chance of having a heart attack in the next five years. The reduction in risk was communicated via relative risk (RR), absolute risk (AR), odds ratio (OR), number needed to treat (NNT), and natural frequencies (NF) respectively. The same information was presented in two pictorial forms (bar graphs and 10x10, 100-people charts). Patients were asked to rank each option according to their preference for communicating the information, whether these formats would encourage them to take this medication every day, and which format best helped them make a decision. They indicated their preference for the type of representation (numbers versus pictures) and whether information should be framed positively or negatively (e.g. 99% success versus 1% failure). The questionnaires included three questions assessing numeracy level aggregated to derive a numeracy score (0–3). This numeracy test has been shown to strongly correlate with accuracy in assessing screening benefit.<sup>18</sup> For a sample questionnaire for a patient with 10% CVD risk, see the Appendix in the online version of this paper.

## Study participants

All adult patients with a CVD risk assessment conducted within four months were eligi-

ble, excluding those unable to speak English, communicate effectively or who were intoxicated. Consenting patients participated via post (mailed and returned questionnaire), telephone (interviewee-assisted completion), or face-to-face within the practice. The face-to-face method was undertaken at a South Auckland general practice, allowing increased recruitment of Māori, Pacific and Indian participants.

#### Analysis

Questionnaire responses were aggregated. Logistic Chi-square test (*p*-value <0.05%) was performed using SPSS version 16.0 by ethnicity and gender for patient preferences for numerical formats, other communication formats, decisionmaking, and for concern for having a heart attack, perceived likelihood of having a heart attack, and keenness to take medication.

#### Results

Of the 376 participants, 178 patients completed face-to-face interviews from 203 eligible patients approached (88% response rate). Practice nurses who recruited study participants via mail (69 participants) or telephone (129 participants) did not record the total number of patients they invited; hence, response rates were not able to be calculated for these methods. The face-to-face recruitment method was significantly more likely to enrol participants of Māori, Pacific and Indian ethnicities compared to telephone interviewing and questionnaires returned by post ( $\chi^2$ =206.9, 2 d.f. *p*<0.0001).

Table 1 provides a summary of the demographic characteristics of participants. The self-reported ethnicity of participants was NZ European/Other 50%, Māori 15%, Pacific 25%, and Indian 10%. Overall, 65% were male; 55% were aged 51–70 years; 34% had their five-year CVD risk estimated as low (<10%), 27% as moderate (10–14%) and 40% as high (>15%).

Patient-reported educational levels ranged from primary school through to university. More NZ European/Other (28%) and Indian (26%) participants had a tertiary education than did Māori (8%) or Pacific (10%) participants. Only 19% of participants answered all three numeracy questions correctly. Most Māori (85%), Pacific (91%) and Indian (74%) participants had low numeracy scores (0 to 1) compared to a minority (35%) of NZ European/Other participants.

# Risk communication using numerical formats

Whereas participants ranked their preferences (1 to 5), the findings are dichotomised into two groups (most and least encouraging, and most and least helpful to understand) for ease of information presentation.

For all ethnicities, RR was ranked as the most encouraging to take medication and most helpful for them to understand their risk (Table 2). Overall NF was the least encouraging format (34%). Indian and Pacific participants were more likely than NZ European/Other and Māori ethnic groups to find NNT least encouraging, compared to other numerical formats ( $\chi^2$ =12.06, 1 d.f. p<0.0001), whereas NZ European/Other and Māori participants were more likely to rank NF as the least encouraging ( $\chi^2$ =21.16, 1 d.f. p<0.0001). Results for most and least easy to understand followed the same ethnic pattern. Pacific participants were more likely than other ethnic groups to rank NF as the second most helpful to understand after RR (χ<sup>2</sup>=36.73, 1 d.f. *p*<0.0001).

# Preferences for means of communicating risk and making treatment decisions

Preferences by ethnicity for various means of communicating risk and making treatment decisions are presented in Table 3.

Māori (64%) and Pacific (58%) participants preferred risk to be presented using pictures than numbers when communicating treatment benefits, compared with NZ European/Other (53%) and Indian participants (49%). All ethnic groups preferred the 100-people chart format compared to the bar graph (Table 3), with Māori, Pacific and Indian participants significantly more likely to prefer this format ( $\chi^2$ =10.01, 1 d.f. *p*=0.002). Two-thirds of all the participants preferred risk information to be positively framed, with no significant difference between ethnic groups ( $\chi^2$ =10.32, 6 d.f. *p*=0.112).

|                       | NZ European/Other<br>(n=187)* | Māori<br>(n=55) | Pacific<br>(n=95) | Indian<br>(n=39) | Total<br>(n=376) |
|-----------------------|-------------------------------|-----------------|-------------------|------------------|------------------|
| Recruitment n (%)     |                               |                 |                   |                  |                  |
| Phone                 | 112 (60)                      | 9 (16)          | 6 (6)             | 2 (5)            | 129 (34)         |
| Mail                  | 56 (30)                       | 11 (20)         | 1 (1)             | 1 (3)            | 69 (18)          |
| Face-to-face          | 19 (10)                       | 35 (64)         | 88 (93)           | 36 (92)          | 178 (47)         |
| Age group n (%)       |                               |                 |                   |                  |                  |
| <40 years             | 5 (3)                         | 6 (11)          | 11 (12)           | 7 (18)           | 29 (8)           |
| 41–50 years           | 30 (16)                       | 18 (33)         | 35 (37)           | 12 (31)          | 95 (25)          |
| 51–60 years           | 54 (29)                       | 18 (33)         | 35 (37)           | 12 (31)          | 119 (32)         |
| 61–70 years           | 57 (30)                       | 8 (15)          | 14 (15)           | 7 (18)           | 86 (23)          |
| >70 years             | 40 (21)                       | 5 (9)           | 0 (0)             | 1 (3)            | 46 (12)          |
| Men n (%)             | 114 (61)                      | 31 (56)         | 64 (67)           | 34 (87)          | 243 (65)         |
| 5-year CVD risk n (%) |                               |                 |                   |                  |                  |
| <10%                  | 73 (39)                       | 11 (20)         | 26 (27)           | 16 (41)          | 126 (34)         |
| 10–14%                | 25 (13)                       | 25 (45)         | 41 (43)           | 10 (26)          | 101 (27)         |
| ≥15%                  | 89 (48)                       | 19 (35)         | 28 (29)           | 13 (33)          | 149 (40)         |
| Education n (%)       |                               |                 |                   |                  |                  |
| Primary               | 5 (3)                         | 3 (5)           | 13 (14)           | 8 (21)           | 29 (8)           |
| Secondary             | 79 (42)                       | 41 (75)         | 64 (67)           | 12 (31)          | 196 (52)         |
| Tertiary              | 102 (55)                      | 11 (20)         | 18 (19)           | 19 (49)          | 150 (40)         |
| Numeracy score n (%)  |                               |                 |                   |                  |                  |
| 0                     | 14 (7)                        | 20 (36)         | 46 (48)           | 13 (33)          | 93 (25)          |
| 1                     | 52 (28)                       | 27 (49)         | 41 (43)           | 16 (41)          | 136 (36)         |
| 2                     | 57 (30)                       | 5 (9)           | 8 (8)             | 5 (13)           | 75 (20)          |
| 3                     | 64 (34)                       | 3 (5)           | 0 (0)             | 5 (13)           | 72 (19)          |

Table 1. Demographic characteristics of participants by ethnicity

Missing data for 1 participant

The majority of all ethnicities (68%) preferred the doctor giving an opinion over explaining risks using numbers and/or pictures, with no significant difference between ethnicities ( $\chi^2$ =0.8967, 3 d.f. *p*=0.826). The most preferred means of decision-making was doctor and patient together on an equal basis (41%). However, Pacific and Indian participants were significantly more likely than NZ European/Other and Māori participants to prefer the doctor to make the decision compared to other decision-making formats ( $\chi^2$ =28.95, 1 d.f. *p*<0.0001).

### Concern about and perceived likelihood of having a heart attack and keenness to take medication

Lastly, Table 4 presents participants' concerns about and perceived likelihood of having a heart attack in the next five years and their keenness to take preventive medication by ethnicity and by their actual CVD risk. Participant five-year CVD risk was grouped as low (<10%), moderate (10–14%) or high (>15%). For NZ European/ Other, concern about having a heart attack increased with increasing CVD risk, whereas for the other ethnicities those at moderate CVD risk were more likely to express extreme concern about having a heart attack than those at high risk.

In those with a high CVD risk score, overall the majority perceived it unlikely that they would have a heart attack, although fewer Māori (21%) and Indian (38%) participants thought this unlikely than Pacific (57%) or NZ European/Other (46%) participants ( $\chi^2$ =8.002, 1 d.f. *p*=0.005).

The majority of participants in all ethnic groups who were at high CVD risk were keen to take medication, with no significant difference between ethnicities ( $\chi^2$ =2.209, 6 d.f. *p*=0.900).

#### Discussion

#### Main study findings

Among 376 primary care patients, this study found ethnic differences in patient preferences for numerical formats, expressing treatment benefits, pictorial presentation and patient preferences for decision-making. Whilst preferences differ amongst individuals, the RR was found to be the most encouraging and helpful to understand numerical format and NF and NNT the least encouraging and helpful, although Pacific people were significantly more likely than other ethnicities to prefer NF. There was a preference for risk to be communicated using pictures. Most participants preferred risk to be framed positively, to be involved in the decision-making process, and preferred the doctor's opinion over risk explanation. The findings of this study highlight that expressing risk and benefits in preferred formats may lead to improved communication and patient understanding. The greater proportion of men in this primary care sample may relate to the target population criteria for CVD risk assessment (i.e. risk assessment 10 years earlier for men).

Table 2. Preference for numerical formats by ethnicity group

|                                |     |   | Ethn            | icity n (%)       |                               |                  |
|--------------------------------|-----|---|-----------------|-------------------|-------------------------------|------------------|
| Preferences*                   |     | NZ European/Other<br>(n=187) <sup>+</sup> | Māori<br>(n=55) | Pacific<br>(n=95) | Indian<br>(n=39) <sup>+</sup> | Total<br>(n=376) |
|                                | RR  | 126 (69)                                  | 36 (65)         | 41 (43)           | 23 (59)                       | 226 (61)         |
|                                | AR  | 27 (15)                                   | 3 (5)           | 9 (9)             | 9 (23)                        | 48 (13)          |
| Most encouraging               | NNT | 10 (5)                                    | 2 (4)           | 3 (3)             | 0 (0)                         | 15 (4)           |
|                                | OR  | 9 (5)                                     | 4 (7)           | 6 (6)             | 1 (3)                         | 20 (5)           |
|                                | NF  | 10 (5)                                    | 10 (18)         | 36 (38)           | 5 (15)                        | 61 (17)          |
|                                | RR  | 3 (2)                                     | 5 (9)           | 4 (4)             | 1 (3)                         | 13 (4)           |
|                                | AR  | 13 (7)                                    | 6 (11)          | 13 (14)           | 1 (3)                         | 33 (9)           |
| Least encouraging              | NNT | 41 (23)                                   | 17 (31)         | 34 (36)           | 22 (56)                       | 114 (31)         |
|                                | OR  | 42 (23)                                   | 8 (15)          | 28 (29)           | 5 (13)                        | 83 (22)          |
|                                | NF  | 83 (46)                                   | 19 (35)         | 16 (17)           | 10 (26)                       | 128 (34)         |
|                                | RR  | 120 (66)                                  | 35 (64)         | 40 (42)           | 20 (51)                       | 215 (58)         |
|                                | AR  | 29 (16)                                   | 6 (11)          | 19 (20)           | 9 (23)                        | 63 (17)          |
| Most helpful<br>to understand  | NNT | 9 (5)                                     | 2 (4)           | 2 (2)             | 0 (0)                         | 13 (4)           |
|                                | OR  | 16 (9)                                    | 4 (7)           | 4 (4)             | 4 (10)                        | 28 (8)           |
|                                | NF  | 8 (4)                                     | 8 (15)          | 30 (32)           | 6 (15)                        | 52 (14)          |
|                                | RR  | 10 (5)                                    | 8 (15)          | 8 (8)             | 1 (3)                         | 27 (7)           |
|                                | AR  | 11 (6)                                    | 5 (9)           | 11 (12)           | 2 (5)                         | 29 (8)           |
| Least helpful<br>to understand | NNT | 30 (16)                                   | 14 (25)         | 36 (38)           | 17 (44)                       | 97 (26)          |
|                                | OR  | 36 (20)                                   | 5 (9)           | 24 (25)           | 7 (18)                        | 72 (19)          |
|                                | NF  | 95 (52)                                   | 23 (42)         | 16 (17)           | 12 (31)                       | 146 (39)         |

AR Absolute risk

NF Natural frequencies

NNT Number needed to treat

OR Odds ratio

RR Relative risk

Only includes Most and Least encouraging and Most and Least helpful to understand because these statistics provide the most useful clinical information

+ Missing data for some participants: NZ European/Other (5), Indian (1)

### Table 3. Patient preferences by ethnicity

|  | NZ European/Other<br>(n=187) | Māori<br>(n=55) | Pacific<br>(n=95) | Indian<br>(n=39) | Total<br>(n=376) |
|--|------------------------------|-----------------|-------------------|------------------|------------------|
| Communication format n (%)*                          |                              |                 |                   |                  |                  |
| Numbers  | 88 (47)                      | 19 (36)         | 40 (42)           | 20 (51)          | 167 (45)         |
| Pictures   | 99 (53)                      | 34 (64)         | 55 (58)           | 19 (49)          | 207 (55)         |
| Pictorial format n (%)*                              |                              |                 |                   |                  |                  |
| Bar graph  | 84 (46)                      | 16 (30)         | 30 (32)           | 10 (26)          | 140 (38)         |
| 100-people chart                                     | 99 (54)                      | 37 (70)         | 65 (68)           | 29 (74)          | 230 (62)         |
| Expressing risk or giving opinion n (%)              |                              |                 |                   |                  |                  |
| Numbers and/or pictures                              | 64 (34)                      | 16 (29)         | 30 (32)           | 11 (28)          | 121 (32)         |
| Doctor's opinion                                     | 123 (66)                     | 39 (71)         | 65 (68)           | 28 (72)          | 255 (68)         |
| Preference for framing n (%)                         |                              |                 |                   |                  |                  |
| 99% successful                                       | 126 (67)                     | 34 (62)         | 58 (61)           | 30 (77)          | 248 (66)         |
| 1% failure   | 19 (10)                      | 7 (13)          | 4 (4)             | 2 (5)            | 32 (9)           |
| No preference  | 42 (22)                      | 14 (25)         | 33 (35)           | 7 (18)           | 96 (26)          |
| Preference for decision-making n (%)                 |                              |                 |                   |                  |                  |
| Doctor make decision                                 | 17 (9)                       | 7 (13)          | 31 (33)           | 12 (31)          | 67 (18)          |
| Doctor make decision but consider<br>patient's views | 40 (21)                      | 7 (13)          | 10 (11)           | 7 (18)           | 64 (17)          |
| Patient and doctor make decision together            | 85 (45)                      | 27 (49)         | 28 (29)           | 15 (38)          | 155 (41)         |
| Patient make decision but consider doctor's opinion  | 45 (24)                      | 14 (25)         | 23 (24)           | 4 (10)           | 86 (23)          |
| Patient make decision<br>based on own opinion        | 0 (0)                        | 0 (0)           | 3 (3)             | 1 (3)            | 4 (1)            |

\* Missing data for some participants: communication format Māori (2); pictorial format NZ European/Other (4), Māori (2)

# Comparison with other studies

The findings of this study are consistent with NZ research that has found that patients prefer information presented as an RR.<sup>15-17</sup> Previous international literature has similarly found that patients prefer the benefits of treatments expressed using RR rather than as an AR or NNT.<sup>19,20</sup> The NNT is not preferred by many patients, suggesting that this format is not easily understood.<sup>21</sup>

Previous literature has also suggested NF are appropriate to use when communicating treatment benefits to individuals with low numeracy because they identify with the reference class, for example, '100 people like me'.<sup>22-25</sup> However, this study found participants had a low preference for this communication method, except for Pacific people for whom this was their second preference after RR. This preference possibly reflects the holistic view of health and social structures in Pacific communities and their extended networks, leading to a preference in numerical formats that considers a group of people.<sup>26</sup>

Previous literature has suggested the use of pictures for communication with Māori.<sup>27</sup> Māori, Pacific and Indian participants showed a greater preference for the 100-people chart format compared to their NZ European/Other counterparts. Pictorial formats are found to aid human processing of quantitative information and are often used to supplement numeric information in the communication of health risks and treatment benefits. This result is consistent with previous studies, indicating that pictures may be an appropriate way to present the risks and benefits of

treatments to patients in shared decision-making environments, particularly among individuals with lower levels of numeracy.<sup>15,23,28-31</sup> The majority of participants in this study preferred risk information to be framed positively rather than negatively, consistent with other NZ research that found 90% of participants preferred positive framing.<sup>15</sup>

The majority of those participants with high CVD risk were not concerned about their risk, and considered it unlikely that they would have a heart attack in the next five years. This is also consistent with previous literature, which has found that individuals are not likely to perceive themselves at risk of CVD, despite their risk factors.<sup>32-34</sup> Misunderstanding of risks can result from various factors, such as low levels of literacy, age, as well as cultural and language barriers.

The majority of participants in this study preferred risk information to be framed positively rather than negatively, consistent with other NZ research that found 90% of participants preferred positive framing

> The majority of the participants were keen to take medication, consistent with a previous NZ study,<sup>15</sup> although that study involved patients in secondary prevention who had already experienced an event and who therefore might be keener to take medication. Although certain ethnic groups (e.g. Indian people) have been found less likely to receive primary prevention treatments-including lipid-lowering and antihypertensive drug treatment—in overseas studies,<sup>35,36</sup> our study found no differences between ethnic groups in keenness to take medication. However, all adult patients with a CVD risk assessment conducted within four months were eligible for inclusion in this study. Hence, it is possible that those identified during the previous four months as high risk had already been commenced on medications and, therefore, this may have had an impact on their preferences reported in the study.

#### Strengths and limitations

A study strength was the use of data collection methods enabling a sample size sufficient for comparison between ethnic groups. Face-toface interviews and careful selection of practices allowed recruitment of Māori, Pacific and Indian peoples and was effective in capturing a high-CVD-risk population. Recruiting from the waiting room allowed for enrolling participants who otherwise might have been missed due to residential address change, not having a telephone or not responding to mailed invitations. However, there is a bias towards those individuals who access their general practice. Face-to-face interviewer bias was minimised by the researcher simply reading the questionnaire to participants and recording their responses where low English literacy required this. While the heterogeneity and high proportion of high-risk populations is a strength, the study did not record the denominator of eligible patients who had been risk assessed in the previous four months, so it is not possible to determine how representative the study population is. The questions in the study also only relate to the preferred method of explanation of risk, rather than assessing what effect this may have on behaviour change in these populations.

Participants self-identified their ethnicity, which is standard practice for the NZ Census. Categories were identified using the NZ Health Information Service ethnicity coding systems, ensuring consistency and quality of data collected. Another key strength was that participants received questionnaires tailored to their known CVD percentage risk, and provided preferences based on their actual risk, rather than a hypothetical situation. This makes the findings more directly applicable to current practice.

A study limitation was the exclusion of non-English speakers; hence, a small number Māori, Pacific and Indian patients were ineligible. The relatively small sample size limits the power of the study to explore cultural variability, such as the likelihood that patients would prefer the doctor to make the treatment decision, versus a more shared decision-making approach. This study finding should be explored in future research.

|   | NZ Eu   | ropean/<br>(n=187)* | Other   |        | Māori<br>(n=55)* |         |         | Pacific<br>(n=95) |         | Ind    | dian (n=3 | 39)     |
|---|---------|---------------------|---------|--------|------------------|---------|---------|-------------------|---------|--------|-----------|---------|
| CVD risk  | Low     | Mod                 | High    | Low    | Mod              | High    | Low     | Mod               | High    | Low    | Mod       | High    |
| Level of concern about having heart attack n (%)    |         |                     |         |        |                  |         |         |                   |         |        |           |         |
| Not concerned                                       | 39 (53) | 7 (28)              | 18 (20) | 3 (27) | 5 (20)           | 3 (16)  | 4 (15)  | 7 (17)            | 6 (21)  | 4 (25) | 2 (20)    | 1 (8)   |
| Somewhat concerned                                  | 24 (33) | 12 (48)             | 36 (41) | 5 (45) | 8 (32)           | 10 (53) | 12 (46) | 12 (29)           | 11 (39) | 6 (38) | 3 (30)    | 8 (62)  |
| Extremely concerned                                 | 10 (14) | 6 (24)              | 34 (39) | 3 (27) | 12 (48)          | 6 (32)  | 10 (38) | 22 (54)           | 11 (39) | 6 (38) | 5 (50)    | 4 (31)  |
| Perceived likelihood of having a heart attack n (%) |         |                     |         |        |                  |         |         |                   |         |        |           |         |
| Not likely  | 59 (81) | 19 (76)             | 40 (46) | 6 (55) | 8 (32)           | 4 (21)  | 8 (31)  | 21 (51)           | 16 (57) | 7 (44) | 5 (50)    | 5 (38)  |
| Somewhat likely                                     | 14 (19) | 6 (24)              | 36 (41) | 5 (45) | 14 (56)          | 12 (63) | 17 (65) | 17 (41)           | 10 (36) | 8 (50) | 4 (40)    | 5 (38)  |
| Very likely   | 0 (0)   | 0 (0)               | 11 (13) | 0 (0)  | 3 (12)           | 3 (16)  | 1 (4)   | 3 (7)             | 2(7)    | 1 (6)  | 1 (10)    | 3 (23)  |
| Keenness to take medicatio                          | n n (%) |                     |         |        |                  |         |         |                   |         |        |           |         |
| Not keen  | 27 (37) | 3 (12)              | 14 (16) | 4 (36) | 3 (12)           | 4 (22)  | 7 (27)  | 6 (15)            | 6 (21)  | 4 (25) | 1 (10)    | 1 (8)   |
| Somewhat keen                                       | 21 (29) | 10 (40)             | 13 (15) | 4 (36) | 10 (40)          | 2 (11)  | 10 (38) | 11 (27)           | 3 (11)  | 6 (38) | 3 (30)    | 1 (8)   |
| Keen  | 25 (34) | 12 (48)             | 61 (69) | 3 (27) | 12 (48)          | 12 (67) | 9 (35)  | 24 (59)           | 19 (68) | 6 (38) | 6 (60)    | 11 (85) |

Table 4. Concern and perceived likelihood of having a heart attack and keenness to take medication by ethnicity and actual CVD risk

CVD Cardiovascular disease

Low = CVD risk <10%

Mod = CVD risk 10-14% (moderate)

High = CVD risk >15%

\* Missing data for some participants: NZ European/Other (1), Māori (1)

#### Implications for practice

Information on risk needs to be communicated in ways that are understandable and meaningful to patients and considered accurate by health professionals. The strong preference for receiving information on risk as an RR by all ethnicities is of potential concern, because a percentage risk reduction is only meaningful if you know your initial absolute risk and how much this may drop with a particular intervention. Our findings suggest that some modes of communication appear to be favoured by members of specific ethnic groups, for example Māori and Pacific people being more likely to prefer pictures to numbers. However, this does not predict what will be preferred by an individual patient. Clinicians, therefore, should routinely use several means of communicating risk and benefit, including pictorial methods, to facilitate improved communication and understanding, leading to better health outcomes. The inclusion of pictorial methods is especially useful with patients with low numeracy or educational attainment, or where English is not the patient's first language.

However, the acceptability of expressing risk and treatment benefits is only a small step towards improved communication and supporting health literacy (defined as the ability to understand and act upon health information). Furthermore, it is only one factor influencing behaviour change and potentially leading to improved longer-term CVD outcomes.

The lack of correlation of participants' concerns that they might have a heart attack in the next five years, or their perceived likelihood that this might happen, with their actual CVD risk indicates that generally patients had limited understanding of what their CVD risk score meant. Regardless of how information is presented, patients may have difficulty comprehending what it means and may prefer a clinical opinion.

Shared decision-making between doctor and patient was most preferred, although Pacific and Indian patients had a greater preference for the doctor to make the decision. Overall, while the participants in this study preferred the doctor's opinion about taking medication over risk

explained using either numbers or pictures, it is important to note that involving patients in decision-making is likely to increase their uptake of preventive measures and, hence, improve health outcomes.

Health professionals may wish to combine numerical data and visual presentations and to cross-check that patients are able to comprehend the information given

> Information on treatment benefits needs to be communicated in various formats, so that patients are assisted to make informed decisions about treatment choices and encouraged to take medication, where indicated. However, different people are likely to have preferences for different information formats that they find easier to understand. While some ethnic differences in preferences have been noted, these do not allow determination of the best method for the individual patient. Health professionals may wish to combine numerical data and visual presentations and to cross-check that patients are able to comprehend the information given.

> When patients truly understand the potential health gains they might derive from specific interventions, both medications and behavioural changes, shared decision-making is facilitated and the chances that the medication will be taken or the lifestyle change adopted will be optimised.

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**COMPETING INTERESTS** None declared.

# **APPENDIX A**

ID number



This questionnaire is about explaining the risks of having a heart attack. Your risk is 10% over the next 5 years.

Below are different ways of expressing your risk of having a heart attack with and without a new medication.

We would like to know the best way to explain to you the benefit of a new medication that has few side effects and is to be taken daily to reduce your chance of having a heart attack.

| Please look at the five statements below and nur | mber them in order | from which is most likely | through to which is | least likely to  |
|--|--------------------|---------------------------|---------------------|------------------|
| encourage you to take a medication every day.    | Most likely = 1    | Next most likely $= 2$    | etc to              | Least likely = 5 |

|   | All these questions apply to a fully funded new medication  | This would encourage<br>you to take this<br>medication every day<br>Most (1) to Least (5) |
|---|---|---|
| а | By taking this new medication for 5 years you will be 33% less likely to have a heart attack  |   |
| b | Without taking this medication your risk of a heart attack in the next 5 years is 10% and with taking this medication your risk is 7% in the next 5 years   |   |
| с | 30 people will need to take this new medication for 5 years for one person to be prevented from having a heart attack   |   |
| d | The odds of you having a heart attack are 9 to 1 without medication and 14 to 1 if you take the medication for 5 years  |   |
| е | There are 100 people like you. If they do not take this new medication then 10 will have a heart attack and 90 will not.<br>If they all take this new medication for 5 years then 7 people will have a heart attack and 3 will be prevented from<br>having a heart attack |   |

Please look at the five statements below again. If you needed to make a decision today about taking a medication every day from now on number the five statements below in order from which one gives you the most helpful information to which one gives you the least helpful information Most helpful information = 1 Next most helpful = 2Least helpful= 5 etc to All these questions apply to a fully funded new medication Indicate if statement helps you to make a decision. Most (1) to Least (5) а By taking this new medication for 5 years you will be 33% less likely to have a heart attack Without taking this medication your risk of a heart attack in the next 5 years is 10% and with taking this b medication your risk is 7% in the next 5 years 30 people will need to take this new medication for 5 years for one person to be prevented from having a С heart attack The odds of you having a heart attack are 9 to 1 without medication and 14 to 1 if you take the d medication for 5 years There are 100 people like you. If they do not take this new medication then 10 will have a heart attack е and 90 will not. If they all take this new medication for 5 years then 7 people will have a heart attack and 3 will be prevented from having a heart attack

**ORIGINAL SCIENTIFIC PAPERS** 

QUANTITATIVE RESEARCH: APPENDIX

Some people prefer to have information about the benefits of medications presented **visually** rather than in **words** as described above. Below are two different ways to show the benefits of treatment using **pictures**.



Picture 2. Here is the risk for 100 people like you having a heart attack in chart form.

The first chart shows the risk over 5 years if the 100 people do not take the new medication. The second graph shows what will happen if all 100 people take this new medication for 5 years to reduce risk of heart attack.



# 100 people on <u>new medication</u> for 5 years



The graph on the page before?

Or the chart on this page? (tick one)

| Do you prefer doctors to explain r  | ks using numbers and /or pictures <u>or</u> do you prefer them to give their opinion on taking   |
|---|--|
| □ Numbers &/or pictures   |  |
| Do you follow horse racing?   | □ Yes □ No   |
| If an operation had a 99% succes<br>□ 99% successful  | rate and a 1% failure rate how would you like it expressed?<br>□ 1% failure □ Don't mind   |
| Imagine that we toss a coin 1,000<br>What is your best guess about ho   | imes.<br>many times the coin would come up heads in 1,000 tosses? times out of 1,000   |
|   |  |
| In a raffle, the chance of winning people each buy a single ticket in   | \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 10 ne raffle? person(s) out of 1,000   |
| In a raffle, the chance of winning<br>people each buy a single ticket in<br>In a sweepstake, the chance of w  | \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 10 ne raffle? person(s) out of 1,000 person(s) out of 1,000%   |
| In a raffle, the chance of winning people each buy a single ticket in In a sweepstake, the chance of w How concerned are you about ha concerned? (please circle one)  | \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 10 me raffle? person(s) out of 1,000 ning a car is 1 in 1,000. What percent of tickets to the sweepstake win a car?% ng a heart attack on a scale of 1 to 10 with 1 being not concerned at all and10 being extreme   |
| In a raffle, the chance of winning people each buy a single ticket in In a sweepstake, the chance of w How concerned are you about ha concerned? (please circle one) Not concerned at all ←1  | \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 10 me raffle? person(s) out of 1,000 ning a car is 1 in 1,000. What percent of tickets to the sweepstake win a car?% ng a heart attack on a scale of 1 to 10 with 1 being not concerned at all and10 being extreme2345678910 $\rightarrow$ Extremely concerned   |
| In a raffle, the chance of winning<br>people each buy a single ticket in<br>In a sweepstake, the chance of w<br>How concerned are you about ha<br>concerned? (please circle one)<br>Not concerned at all ←1<br>What was your last formal <b>educa</b> | \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 10 me raffle? person(s) out of 1,000 ning a car is 1 in 1,000. What percent of tickets to the sweepstake win a car?% ng a heart attack on a scale of 1 to 10 with 1 being not concerned at all and10 being extreme2345678910→ Extremely concerned on?Primary schoolHigh school. If high school at what level did you finish? |

| <b>Age</b> :<br>70 | □ ≤30<br>□ >70           | □ 31-35               | □ 36-40           | □ 41-45          | □ 46-50            | □ 51-55                  | □ 56-60                    | □ 61-65             | □ 66-     |
|--------------------|--------------------------|-----------------------|-------------------|------------------|--------------------|--------------------------|----------------------------|---------------------|-----------|
| Which              | ethnic grou              | <b>p</b> do you belor | ng to? (Tick the  | box or boxes     | which apply to     | you)                     |                            |                     |           |
| □ NZ               | European                 | □ Māori               | □ Cook Isla       | nd Māori         | □Samoan            | □Tongan                  | D Niue                     | ean                 | □ Chinese |
| 🗆 Indi             | ian                      | □Other (s             | uch as Dutch, 、   | Japanese, Tok    | elauan) Please     | state                    |                            |                     |           |
| How do             | o you feel ab            | out taking med        | dication daily fo | r the rest of yo | our life to help p | revent heart atta        | acks? (please              | circle <u>one</u> ) |           |
| Not kee<br>mee     | en to take ←<br>dication | 12                    | 4.                | 6.               | 7                  | 8910                     | → Keen to ta<br>medication | ke<br>on            |           |
| How lik            | ely do you tl            | nink it is that y     | ou will have a    | heart attack in  | the next 5 yea     | rs with 1 being i        | not likely to 10           | being very          | likely?   |
|                    | Not likely ←             | 12                    | 34                | 5                | .67                | 89                       | 10 → Very lił              | cely                |           |
| When c             | considering t            | aking medicat         | ion to reduce th  | e risk of a hea  | irt attack please  | e tick the <u>one</u> or | otion that you I           | ike the <b>best</b> |           |
| (a) 🗆 T            | he doctor sh             | ould make the         | e decision        |                  |                    |                          |                            |                     |           |
| (b) □Tł            | he doctor sh             | ould make the         | decision, but c   | onsider the pa   | tient's views      |                          |                            |                     |           |
| (c) ⊟Tł            | ne patient ar            | d the doctor s        | hould make the    | e decision toge  | ther on an equa    | al basis                 |                            |                     |           |
| (d) 🗆 T            | he patient s             | hould make th         | e decision but o  | consider the do  | octor's opinion    |                          |                            |                     |           |
| (e) 🛛 T            | he patient s             | hould make th         | e decision base   | ed on his/her o  | wn opinion         |                          |                            |                     |           |
|                    |                          |                       |                   | т                | hank vou           |                          |                            |                     |           |
|                    |                          |                       |                   |                  | папк уой           |                          |                            |                     |           |
|                    |                          |                       |                   |                  |                    |                          |                            |                     |           |