

A Kaupapa Māori approach to a community cohort study of heart disease in New Zealand

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Within New Zealand, significant health disparities exist between Māori (the indigenous population) and non-Māori.^{1,2} Cardiovascular events are the leading cause of mortality within the Māori population³ and therefore a health priority for Māori. The mortality statistics for 2000-2004 illustrate this disparity between the two populations (Māori:non-Māori mortality rate ratios for ischaemic heart disease (IHD) 2.25, stroke, 1.61, heart failure 2.3 and rheumatic heart

disease 7.46). In addition, there is earlier onset of cardiovascular events within the Māori population. For Māori, 45% of deaths with IHD occurred before the age of 65 years, compared with 11% for non-Māori.⁴ Among those aged 45-64, Māori:non-Māori mortality rate ratios for IHD were 4.69 for females and 3.01 for males. Heart failure mortality rate ratios for those aged 45-64 were 4.8 for females and 10.4 for males.⁴ Current literature has identified barriers to cardiovascular screening and interventions

Abstract

Objective: To report the processes and protocols that were developed in the design and implementation of the Hauora Manawa Project, a cohort study of heart disease in New Zealand and to report the participation at baseline.

Methods: This study utilised application of a Kaupapa Māori Methodology in gaining tribal and health community engagement, design of the project and random selection of participants from territorial electoral rolls, to obtain three cohorts: rural Māori, urban Māori and urban non-Māori. Logistic regression was used to model response rates.

Results: Time invested in gaining tribal and health community engagement assisted in the development and design of clear protocols and processes for the study. Response rates were 57.6%, 48.3% and 57.2%. Co-operation rates (participation among those with whom contact was established) were 74.7%, 66.6% and 71.4%.

Conclusions: Use of electoral rolls enables straightforward sampling but results in low response rates because electors have moved. Co-operation rates highlight the acceptability of this research project to the participants; they indicate the strength of Kaupapa Māori Methodologies in engaging Māori participants and community.

Implications: This study provides a model for conducting clinical/biomedical research projects that are compatible with cultural protocols and methodologies, in which the primary aim of the research was Māori health gain.

Key words: Indigenous population, ethnic groups, cardiology, heart diseases

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for Māori⁵⁻¹² and has advocated specific steps to decrease current disparities.^{13,14}

The main aims of Hauora Manawa/Heart Health: The Community Heart Study (hereafter referred to as the Hauora Manawa Project) were to collect prevalence data for heart disease within randomly selected samples from two different Māori Communities (Ngati Kahungunu ki Wairoa in rural Hawkes Bay and Ngai Tahu ki Waitaha in urban Christchurch), and a non-Māori urban Christchurch cohort, to identify objective markers to guide monitoring of cardiovascular disease risk (as determined by the New Zealand cardiovascular guidelines):¹⁵ within these communities and to follow and document the implementation and outcomes of interventions for study participants. Participants obtained a free cardiovascular screen and risk assessment, a free visit to their general practitioner (GP) if required and a direct referral to a free cardiology assessment within the public health system if clinically indicated.

The rural Wairoa District is in Northern Hawkes Bay with a population of 8,481 people, of whom 60.7% identified as Māori.¹⁶ It is two hours north of the closest, fully serviced hospital.

Christchurch is the largest city in the South Island and is midway down the east coast, in the Canterbury region. In 2006 the population was 348,435, of whom 7.6% identified as Māori, and 75.4% identified as New Zealand European.¹⁷ Christchurch Hospital is a large (600–650 bed) tertiary, teaching and research hospital and provides a full range of emergency, acute, elective and outpatient services.

The purpose of this paper is to report the processes and protocols that were developed in the design and implementation of the Hauora Manawa Project and the outcomes in terms of participation at baseline. The focus is first on the complexities of working alongside indigenous tribal authorities and regional health authorities for this project. Secondly, this paper will discuss the use of random selection in this context.

Methods

Defining the Māori population

In the past, a number of definitions of ‘Māori’ have been applied, however since 1986, self-identification of ethnicity has become the standard practice.¹⁸ In the census, people can report multiple ethnicities. Anyone listing Māori is counted as Māori under both prioritised and total response analyses.^{19,20} The Ministry of Health in New Zealand uses the census ethnicity question and protocol.^{21,22} Within the 2006 census 565,329 of New Zealanders identified as Māori (15%; although 18% of the total population indicated that they had Māori ancestry).²³ Ethnicity is not recorded on the electoral roll; however electors indicate whether or not they are of Māori descent.

For the purposes of this research, Māori participants were defined as those identified on the electoral roll as descended from a New Zealand Māori and who, at interview, confirmed descent and self-identified as New Zealand Māori.²⁴

Kaupapa Māori Methodology

The Hauora Manawa Project utilised a Kaupapa Māori Methodology,²⁵ a conceptual framework that places Māori values, beliefs and experiences at the centre of the research process and locates resultant data within that social context. It provides a means of critiquing systems and structures with regard to their impact on Māori participants and their communities. Past uncritical research has under-served Māori as a result, for example, of data being misapplied to reinforce stereotypes, failure to disseminate results appropriately and a focus on progressing academic research careers without capacity building within the researched community. Kaupapa Māori Methodology dictates that the lead investigator is Māori. Within the Hauora Manawa Project the lead investigator and other Māori research members belonged to either or both of the involved tribal groups, Ngati Kahungunu or Ngai Tahu. This ensured high levels of accountability between the research project and the tribal authorities.

Within this specific project Kaupapa Māori Methodology was applied by working alongside two tribal authorities (appropriate to each region) Ngati Kahungunu ki Wairoa Taiwhenua (Wairoa Cohort) and Mana Whenua ki Waitaha (Christchurch cohort) to ensure clinical and research study protocols were culturally appropriate, including:

- ensuring all data gathered was for the specific purpose of the project and aligned with research aims and objectives;
- all questionnaires, clinical protocols, recruitment and retention approaches were seen as appropriate for Māori;
- on identifying any cardiovascular risk factors direct referrals would be made for participants to either their GP and/or to cardiology services at no cost to the participant;
- , in line with cultural imperatives of reciprocity, participants received a small koha for participating (koha is a gift, in this case a study T-shirt, petrol voucher and University of Otago merchandise);
- in Wairoa (due to limited health resources) the study would provide free screening to a few non-selected community members identified as being at elevated risk for cardiovascular disease (this data was not included in the study analyses);
- all research team members could enact basic protocols to ensure culturally accepted processes occurred within the clinics and could be involved in traditional rituals associated with the implementation of the study (e.g. powhiri [welcome ceremony], karakia [prayer], poroporoaki [farewell ceremony]);
- dissemination of participant data would be done in a way that was meaningful to participants, including via ongoing community updates through local papers, research newsletters and meetings;
- analysis of the data was reviewed by the entire research team, who would undertake to frame results within Māori realities; and
- the primary aim of the research was Māori health gain.

Subsequent consultation was undertaken with the Hawkes Bay and Canterbury District Health Boards and relevant regional primary healthcare organisations. This ensured that all stakeholders had an opportunity to be part of the research development process.

It also ensured that the process of utilising local health services in the triaging process (e.g. GP and cardiology referral) was clearly outlined and agreed to before the commencement of the project. This included agreement about who would meet which costs.

The study also had to meet scientific standards and was assessed by grant bodies. Ethics approval was gained from the Multi-Region Ethics Committee (MEC/06/03/026).

Sampling

Sample size calculations were based on previous estimates of cardiovascular disease, diabetes and their risk factors in the general population, in the range of 5-25%.²⁶ Risk increments for Māori above these levels of >7% for the lowest prevalence risk factors and >12% for the highest prevalence risk factors, would be detectable in pair-wise comparisons with samples of 250 Māori participants per region and 250 non-Māori in Christchurch (power=80%, $\alpha_2=0.05$).²⁷ The number required to be selected from electoral rolls to obtain this number of participants was estimated by assuming a 65% response rate. In addition, for the Māori samples it was expected that 12.8% of people of Māori descent would not identify their ethnicity as Māori.²⁴ With rounding up to the nearest 10, this required 450 people of Māori descent to be selected at each site, and 391 not of Māori descent to be selected in Christchurch.

Selection was from the territorial electoral roll for Wairoa District and the electoral roll for Christchurch City, excluding Banks Peninsula Ward (a largely rural area that amalgamated with Christchurch City in March 2006). People registered at a Christchurch address but with a mailing address outside Christchurch were also excluded from the Christchurch sample (2.7%). For health research, the Electoral Office provides age in one-year bands. Electoral rolls including people aged 20-64 years were provided on 16 November 2006, for Wairoa and 19 January, 2008 for Christchurch (clinics were run in Wairoa in 2007 and in Christchurch in 2008).

Sample selection was carried out in SAS 9.1 using PROC SURVEYSELECT, taking a simple random sample without replacement from each stratum, specifying the number to be selected. The roll was stratified by age (20-29 / 30-39 / 40-49 / 50-64) and by sex (for determination of sex from the electoral roll see <http://www.chmeds.ac.nz/research/chs/methods>). For the Māori descent samples, everyone in the age range 20-64 years had an equal probability of selection. The Christchurch non-Māori descent selection was frequency matched to the sex- and age-group distribution of the Christchurch Māori descent sample.

In both regions it became clear that the desired sample size would not be achieved, both because of low response rates and because of people moving out of the area, and so no longer being eligible. An additional 92 people of Māori descent were selected in Wairoa, an additional 210 people of Māori descent in Christchurch and an additional 140 people not of Māori descent in Christchurch, all selected as before. Therefore, the total percentage selected from the roll was 20.6% of Māori descent in Wairoa (542/2636), 4.4% (660/15152) of those of Māori descent in Christchurch, and 0.3% (531/169,739) of those not of Māori descent in Christchurch.

In Wairoa, 18 members of the community who had not been selected were screened, as in agreement with the local tribal authority. Of these people, five were referred back to their GP for further health care.

The pilot clinic

A purposive sample of 10 community members was used to trial the research tools and clinical protocols. A purposive sample²⁸ is one which samples for a 'purpose', in this case to obtain individuals with a range of ages, health status and tribal affiliation. Three adjustments followed this pilot clinic. The first change was the development of a cotton gown for participants to wear during echocardiogram and electrocardiograph (ECG) procedures, which preserved individual privacy but did not prevent appropriate clinical etiquette. The second change was that venupuncture did not involve pillows (associated with use for the head) for arm support, but instead alternative arm support was developed. Third, the order of the clinical procedures was changed to ensure more time efficiency. These changes supported the inclusion of appropriate cultural protocols within clinical procedures.

Interview and clinical examination

Potential participants were first sent an invitation letter and information package to explain the overall study, along with pre-paid response form with phone and other contact details. Those who did not respond to the first mail out were followed up with a reminder postcard, then follow-up phone calls, house visits, a second letter and finally a second round of phone calls. Participants were booked via phone into a scheduled clinic appointment. At the time of assessment, participants provided informed, signed consent to participate in the project, and were interviewed with a structured questionnaire of 48-68 questions, depending on responses; this usually took 15-25 minutes. Initial and resting blood pressures were taken 20 minutes apart, followed by a fasting blood sample for full blood differential cell counts (Wairoa Hospital Laboratory, Hawkes Bay District Health Board or Canterbury Health Laboratories, Canterbury District Health Board); plasma lipid profiles, glucose, insulin, creatinine, homocysteine, urate and HbA1c (Canterbury Health Laboratories). Plasma was stored for subsequent measurement of cardiac hormones and novel biomarkers, and blood leukocytes collected for extraction of DNA for investigation of genetic markers of cardiovascular disease risk (conditional on participant providing explicit consent to DNA analysis being given on the consent form). If the participant was not fasting, an alternative time was organised for blood sampling. The participants were then taken to the next room and offered a 'purpose-built' gown for the ECG and echocardiogram. Anthropometrics and body composition measurements were recorded (Tanita TBF 310 Body Composition Analyzer, Tanita Inc, Tokyo, Japan). Finally, the participant met with either a GP or cardiologist team member to explore nine further clinical questions, and have a general discussion about their overall health (questionnaires are available at <http://www.chmeds.ac.nz/research/chs/methods.htm>). Participants spent between one

and 2.5 hours within the clinical process. Travel expenses were reimbursed. Refreshments were available for all participants at the conclusion of their visit.

Final disposition codes and response rates

The final disposition for each person selected was coded according to the American Association for Public Opinion Research (AAPOR) guidelines for in-person household surveys and response rates were calculated conservatively using Response Rate 1 which includes all persons of unknown eligibility in the denominator (http://www.aapor.org/uploads/Standard_Definitions_04_08_Final.pdf). The only modification for the baseline of a cohort study was that people unable to participate in the cohort study through physical or mental incapacity were excluded as not eligible. In this context 'Interviewed' means 'attended a clinic where they were interviewed and examined'. There are four main outcomes: Interviewed (I); Eligible but not Interviewed (EI); Unknown Eligibility (UE); and Not Eligible. The EI group is subdivided into those who were contacted but did not attend a clinic (REF) and the no contact group (NC).

$$RR = \frac{I}{I + (REF + NC) + UE} \quad COOP = \frac{I}{I + REF}$$

Statistical analysis

Analyses were carried out in SAS 9.1. Confidence intervals for proportions were calculated using the binomial distribution, using exact calculations where appropriate. Logistic regression

was used in analysis of response rates with three predictors (age group, sex and sample) and Wald chi-square tests were used to evaluate significance. For pair-wise comparisons between samples two logistic regressions were carried out, changing the reference sample.

Results

Response rates

The overall response rates were 57.6% (95% CI 53.0, 62.2; 254/441) for the Wairoa Māori descent sample, 48.3% (95% CI 44.1, 52.4; 267/553) for the Christchurch Māori descent sample, and 57.2% (95% CI 52.7, 61.8; 257/449; 254/340) for the Christchurch Non-Māori descent sample. The co-operation rates were 74.7% (95% CI 70.1, 79.3) for the Wairoa Māori descent sample, 66.6% (95% CI 62.0, 71.2; 267/401) for the Christchurch Māori descent sample, and 71.4% (95% CI 66.7, 76.1; 257/360) for the Christchurch Non-Māori descent sample. Full listing of disposition codes for each sample is available (Table 1: <http://www.chmeds.ac.nz/research/chs/methods.htm>).

Of the 778 participants across the three samples, 37.5% came in response to the initial invitation letter, only 1.4% responded to a reminder postcard, 13.8% were enrolled through the first round of phone calls, 33.4% through visits from team members or contacts through health providers, 7.3% from a follow-up letter and the final 6.6% from a second round of phone calls. The only difference across the samples was in response to the follow-up letter which resulted in 26 and 24 responses in Christchurch but

Table 1: Response rates in each sample by age and sex as determined from the electoral rolls.

Age group	Males				Females			Total	
	N selected	N not excluded ^a	N of interviews	Response rate ^b	N selected	N not excluded ^a	N of interviews	Response rate ^b	Response rate ^b
Wairoa Māori descent sample									
20-29	58	36	10	27.8	66	46	22	47.8	39.0
30-39	58	50	27	54.0	71	56	32	57.1	55.7
40-49	64	53	26	49.1	78	67	40	59.7	55.0
50-64	76	69	47	68.1	71	64	50	78.1	72.9
Total	256	208	110	52.9	286	233	144	61.8	57.6
Christchurch Māori descent sample									
20-29	91	69	21	30.4	106	82	23	28.1	29.1
30-39	86	70	35	50.0	95	80	38	47.5	48.7
40-49	73	65	34	52.3	78	69	45	65.2	59.0
50-64	71	64	34	53.1	60	54	37	68.5	60.2
Total	321	268	124	46.3	339	285	143	50.2	48.3
Christchurch Non-Māori descent sample									
20-29	73	54	22	40.7	85	64	20	31.3	35.6
30-39	69	56	30	53.6	76	63	38	60.3	57.1
40-49	59	51	34	66.7	63	59	38	64.4	65.5
50-64	57	54	41	75.9	49	48	34	70.8	73.5
Total	258	215	127	59.1	273	234	130	55.6	57.2

Notes:

a) Excluded those not eligible as not living in the area, or dead or physically or mentally unable/incompetent.

b) Calculated as per AAPOR (http://www.aapor.org/uploads/Standard_Definitions_04_08_Final.pdf).

only seven in Wairoa. The use of a Māori name for the study (even with an English translation) and a Māori motif on all information seemed to confuse some non-Māori, as at door-to-door contact many agreed to participate, but said that they had not thought they were eligible, because they thought the study was only for Māori and that they had been selected by mistake.

Over the three sites the recruitment costs incurred were \$11,960 for Wairoa, \$9,251 for Christchurch Māori and \$8,548 for Christchurch non-Māori, amounting to \$29,760 in total or \$38 per person recruited into the cohorts.

Table 1 shows the response rates for each of the age and sex groups for each sample. These were analysed in a joint model with age group, sex and sample as predictors. The lowest response rate was from 20-29 year olds and the highest from 50-64 year olds (four age groups, $\chi^2=88.8$, $df=3$, $p<0.0001$). Females were only slightly more likely to respond than males (55.5% versus 52.2%) and this difference was not quite significant ($\chi^2=2.9$, $df=1$, $p=0.09$). Response rates did differ across the samples ($\chi^2=8.3$, $df=2$, $p=0.02$). The Wairoa Māori descent sample and the Christchurch Non-Māori descent sample did not differ ($\chi^2=0.6$, $df=1$, $p=0.44$) but the Christchurch Māori descent sample had a lower response rate than the other two samples ($\chi^2=7.7$, $df=1$, $p=0.006$ versus Christchurch Māori sample; $\chi^2=3.7$, $df=1$, $p=0.05$ versus Wairoa sample). As the electoral roll did not supply gender, there were discrepancies between gender as determined from forenames on the electoral roll and gender as reported by the participants: eight of 361 'males' were female and one 'female' was male (out of the 778 who attended a clinic). For response rate calculations it was necessary to use gender and Māori descent as determined from the electoral roll as corrections were possible only for participants, not for non-participants.

Cohorts at baseline

Exclusions ensured appropriate cohort membership for all subsequent analyses.

Wairoa Māori exclusions: Two participants, one who was much older than 64 years of age and another who did not report Māori ethnicity. Three participants had turned 65 by the time they attended a clinic but had been under 65 at the time of sample selection; these were counted as still in the 50-64 age group.

Christchurch Māori exclusions: The 24 participants of Māori descent who did not report Māori ethnicity.

Christchurch Non-Māori exclusions: One participant selected as part of the non-Māori descent who reported being of Māori descent and ethnicity at interview.

Discussion

This paper has described the processes and protocols involved in the setting up of the Hauora Manawa Project, in particular the Kaupapa Māori Methodology, the use of random selection from the territorial electoral rolls to obtain three cohorts, and the resulting response rates.

Engagement with tribal authorities and regional health authorities.

Engagement with stakeholders was a lengthy process (12-18 months) that included multiple discussions about specific clinical processes, as well as general research protocols. Thus, the project was reviewed by a large stakeholder group, who provided valuable feedback regarding all aspects of the project, including screening, referral, cost allocations and other stakeholder support. Both indigenous tribal authorities and regional health authorities provided relevant support letters that assisted in obtaining funding for this research. The collaborative approach also ensured that study processes needed only relatively minor amendments once the project started. It also contributed to stakeholders actively promoting the study and encouraging participants to take part. Research participants reported feeling welcome within the clinical environment and commented positively on the presence of Māori and other 'friendly' clinicians. Many specifically noted their appreciation of the ECG/echocardiography gown; they reported that this integrated clinical practice with Māori cultural beliefs.

Random selection

Within the Wairoa district there was great concern over the use of random selection. This was in large part due to the limited health resources within the rural community, and hence it was seen as unfair that only some Māori would benefit from the screening and intervention. Although random selection was not viewed as entirely compatible with the concept of Māori collective privilege, after discussion between team and Māori tribal authorities, it was agreed that this approach was necessary to determine prevalence rates accurately. To ensure that the concept of Māori collective privilege was not ignored, the research team agreed to screen some additional members of the community, on the basis of need, whose data would not be included in the study. This approach was accepted by the Ngati Kahungunu ki Wairoa Taiwhenua as appropriate practice and ensured their continued endorsement of the project.

Electoral roll sampling was used in the Hauora Manawa Project because it more readily enables selection of Māori than areal sampling or random digit dialling of telephones. New Zealand territorial authority electoral rolls contain an indicator of Māori descent, because only those of Māori descent can vote in parliamentary Māori electorates, although they may choose to be on the parliamentary general roll instead. About 81% of those who reported Māori descent at the last census in 2006 also reported Māori ethnicity (<http://search.stats.govt.nz/search?w=quick%20stats%20on%20maori>, Tables 1 and 27). The electoral rolls do not provide information relevant to any other ethnic group. By sampling those of Māori descent on electoral rolls it is possible to have equal probability of selection.

Nonetheless there are some disadvantages of electoral roll sampling for Māori. As not all those of Māori descent report Māori ethnicity (<http://www.stats.govt.nz/>

census/2006censushomepage/quickstats/quickstats-about-a-subject/maori.aspx), decisions have to be made about inclusion of these participants. To keep a clear distinction between Māori and non-Māori ethnicity, participants self-identifying with an ethnic group different from the cohort for which they were selected (one in Wairoa, 25 in Christchurch) were retained in the study for treatment and follow-up but excluded from cohort analysis. Errors in the Māori descent indicator on the rolls appear to be very minor; of the 521 participants selected as of Māori descent, only one said that was incorrect. Similarly, only one of the 257 participants selected as not of Māori descent, reported being of Māori descent.

Electoral roll coverage of the target population is a more major issue, both for Māori and non-Māori. Comparison of enrolments with census data indicates an overall coverage of 93.1%, but this is lower for 18-24 year olds (75.9%) and 25-29 year olds (87.8%) (http://www.elections.org.nz/ages/electorate_all.html).

For a regional study, movement out of the area since the Electoral Roll was provided means that the selected elector is no longer eligible. In the Hauora Manawa Project, at each site, all selected electors were simultaneously mailed the initial invitation to participate, but clinics were run over the subsequent year. Therefore, failure to contact potential participants was higher than in an areal survey and consequently the difference between the overall response rate and the co-operation rate was larger than in an areal survey. In the Hauora Manawa Project, out of the 1,733 electors selected, only 11 were known to be eligible but could not be contacted, but 330 had moved or were unable to be contacted to find out if they had moved, so that only 80.3% of those selected were actually contacted, in spite of extensive attempts. Therefore, even with co-operation rates of 66.6-74.7%, overall response rates were only 48.3-57.6%. The last New Zealand Health Survey indicates the advantage of areal studies in terms of establishing eligibility because at least someone in the household is contacted (<http://www.moh.govt.nz/moh.nsf/indexmh/methodology-report-2006-07-nz-health-survey>): 91.8% of households were contacted so that, even though the co-operation rate from those households was only 74.5%, the overall unweighted response rate was 68.1%. This survey involved a 1-1.5 hour interview in the participant's home. For the Hauora Manawa Project, individuals had to come into a clinic for a 1-2.5 hour screening (including fasting and blood collection) and so it is surprising that the co-operation rates were close to those for the New Zealand Health Survey.

Conclusions

Using a Kaupapa Māori Methodology for this project resulted in high levels of engagement of both tribal authorities and Māori participants, as indicated by attendance at research community feedback meetings and willingness to allow their stories to be documented using video media. It also provided a transparent platform in which to work alongside regional health

authorities. It simplified strategies around clinical protocols and processes and their alignment with Māori cultural beliefs, while also ensuring stakeholders' opinions and ideas were included within the research. The use of Kaupapa Māori Methodology that dictated the project be Māori-led, also supported a multi-cultural team to establish how things would be undertaken in the study and provided professional development opportunities for non-Māori research and clinical staff to develop cultural expertise and engage with Māori communities.

However, it was also noted that in an attempt to ensure that the research was attractive to Māori and encouraged their participation, these same tools also became a barrier to some non-Māori participation. Door-to-door contact revealed that because potential participants had noted the Māori language and motifs they did not read the study invitation letter. Future research projects looking to utilise comparative indigenous and non-indigenous groups need to determine whether more than one marketing approach is needed for the research project to target participation from all population groups.

This paper has reported the lessons learnt within the recruitment phase of this cohort study (stage one). Stage two includes a follow-up clinic at two years after baseline screening, to assess interventions experienced and changes in cardiovascular risk over the intervening two years.

Acknowledgements

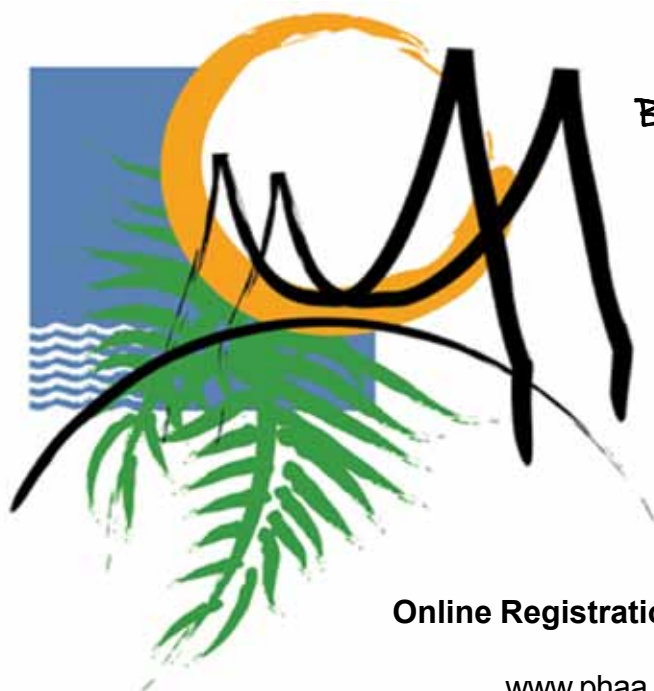
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