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## **Developing a Strategic Research Program for Addressing Cardiovascular Disease and Related Disorders in Aboriginal and Torres Strait Islander Peoples and Rural and Remote Settings**



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# Developing a strategic research program for addressing cardiovascular disease and related disorders in Aboriginal and Torres Strait Islander peoples and rural and remote settings

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Strategic change is important in order to address priority needs. To be successful, sound planning and development processes are necessary. This paper presents a success story of achieving significant strategic change within the National Heart Foundation (NHF), and using this financial commitment to negotiate a collaborative funding arrangement with the Commonwealth Department of Health and Aged Care (DHAC). This has resulted in a substantial increase in funding for priority and strategic research in cardiovascular disease (CVD) and related disorders in Aboriginal peoples and Torres Strait Islanders and rural and remote populations.

## BACKGROUND

### NHF Rural, Remote, Aboriginal and Torres Strait Islander Program

Early in 1998 the NHF initiated a priority program for Aboriginal peoples, Torres Strait Islanders and rural and remote populations. Shortly after the commencement of the program, the Rural, Remote, Aboriginal and Torres Strait Islanders advisory committee (RRAAC) was convened to provide strategic direction and advice. This committee comprises a range of academics, health service providers and representation from government and non-government organisations. RRAAC has expertise in public health, epidemiology, clinical care, health services, policy development and planning for Aboriginal peoples and Torres Strait Islanders and rural and remote settings and has been active in planning for strategic health care and research in CVD in these areas.

### History of the NHF research program

The NHF has provided \$79 000 000 (actual) which is equivalent to \$138 000 000 in real terms for research in the past 40 years. As stated in the NHF Business Plan 1999:

Peer reviewed basic [scientific] and clinical research and individual funding of Research Fellows, Scholars and travel grants continues as a crucial aspect of the Foundation's work. Priority areas include clinical research, public health and epidemiology, behavioural research, and research among socially disadvantaged groups including Indigenous populations.

Professor Tonkin of the NHF recently stated "We are advancing rapidly in basic scientific research [but] by contrast public health research and social research have been relatively neglected. A process was developed to address this deficit particularly

in research into CVD in Aboriginal peoples and Torres Strait Islanders and rural and remote populations.”<sup>1</sup>

## PROCESS FOR STRATEGIC CHANGE

### Reviewing research and identifying priorities

In 1998 the NHF decided to review their research program. To inform this process RRAAC developed an options/discussion paper. This paper was circulated widely, internally and externally, for comment. The final document was presented through the internal NHF committee structure. The response to the document indicated that the points raised would be considered in the development of the generic NHF research program. No immediate action was apparent. This response is to be anticipated when radical change is being proposed. However the paper provided the opportunity to put forward issues identified by Wills, such as priority and strategic research, and evaluation and dissemination research<sup>2</sup> as an alternative to investigator driven, fundamental and clinical research that had been the predominant in the NHF research program since inception<sup>3</sup>.

During this time RRAAC decided to progress the recommendations of the DHAC National Health Priority Area report on Cardiovascular Health that related to heart disease in Aboriginal peoples and Torres Strait Islanders and rural and remote populations. A workshop was held in Townsville in October 1999, which used the experience of workshop participants to suggest actions to implement the report’s recommendations and develop solutions to inform national policy. There were close to 100 participants, including representatives of the National Aboriginal Community Controlled Health Organisation (NACCHO), DHAC, Divisions of GPs, clinicians, non-government organisations and relevant academic institutions.

As well as this, a process was developed to determine strategic research priorities for cardiovascular disease (CVD) in Aboriginal peoples and Torres Strait Islanders and rural and remote settings. The research planning group included representatives of the NHF, the Centre for Remote Health (Flinders and Northern Territory Universities), the South Australian Centre for Rural Health, NACCHO, Edith Cowan University, the University of Melbourne and Monash University. This group met regularly and designed and implemented literature reviews of the state of knowledge about CVD in Aboriginal peoples and Torres Strait Islanders and rural and remote settings. The information was provided for a workshop held in Alice Springs in November, 1999, to review current research and determine future research priorities for the focus areas.

This workshop was co-hosted by the NHF Rural, Remote, Aboriginal and Torres Strait Islander Program and the Centre for Remote Health. It brought together over 40 key researchers, community representatives, policy makers and health practitioners. The information from the Townsville workshop was fed into this process.

The task of the workshop was to consider the needs of rural and remote non-Indigenous populations, as well as rural, remote and urban Indigenous populations, and to identify the research necessary to improve health outcomes related to CVD.

Through this rigorous process we were able to build up an accurate and comprehensive picture of current knowledge and identify strategic research priorities.

### Gaps in knowledge

The findings of the combined processes indicated that research work in this area has been predominantly descriptive, with few intervention studies, evaluation or dissemination research, public health, sociological or behavioural research.

The evidence presented from some of the descriptive studies is that there is no significant difference in the health of rural and remote populations compared with urban populations, when Aboriginal and Torres Strait Islander people are considered separately<sup>4,5</sup>. This remains contentious and is based on highly aggregated data. Regardless of the arguable difference in health status between rural and urban populations, hospitalisation rates are higher, and lengths of stay longer in the bush compared with the city<sup>4</sup>.

### Rural and Remote non-Indigenous people

There is some regional evidence that people living in rural and remote areas have poorer health status, including higher rates of cardiovascular disease (CVD), and reduced access to services compared with their metropolitan counterparts<sup>6,7,8</sup>. It has been demonstrated that hospital mortality in non-metropolitan hospitals is higher than in metropolitan hospitals, after adjusting for severity of disease<sup>9</sup>. The authors of this study propose that this may be partly explained by the difference in treatment regimens between rural and urban settings. Another study demonstrates that the rate of access to procedures is comparatively poorer in rural and remote areas<sup>10</sup>.

These findings not only indicate that there are significant inequalities in health status, treatment, access and outcomes but also that these issues need to be further investigated as there is insufficient comparable regional information that can be used to make informed decisions.

### Aboriginal peoples and Torres Strait Islanders

The review served to confirm that CVD continues to be the highest cause of mortality in Indigenous and non-Indigenous people. Across all age groups Aboriginal peoples and Torres Strait Islanders are known to die from CVD at twice the rate of other populations<sup>11</sup>. However, in the 25–45 year age group the mortality rates are up to 15 times higher<sup>12</sup>. The higher rates of CVD in Indigenous populations is further compounded by rates of diabetes that are up to 16 times higher than in non-Indigenous populations<sup>13</sup>. This indicates a very serious situation that needs increased research that contributes to decreasing these alarming mortality rates.

A significant finding of the research review was that very few interventional studies had been undertaken. This debunks the statement that “Aboriginal people are over researched”, the more accurate statement is that Aboriginal people are “over counted” and their health status “over described”.

## Identified research priorities

As a result of the process outlined above the following research priority areas have been identified<sup>14</sup>:

- ◆ interventions re risk factors for CVD and the associated cluster of risk factors (poor nutrition, sedentary lifestyle, and tobacco) for non-communicable disease, eg diabetes, renal, hypertension, stroke, some cancers;
- ◆ food supply issues;
- ◆ strategies to enhance community control and participation in all processes including health services and also individual power and control over the environment, health risk factors and disease;
- ◆ models of health care;
- ◆ addressing social and economic inequalities;
- ◆ improved information relating to epidemiology, access, quality and data collection; and
- ◆ building shared cultural understanding.

The workshop participants concluded that research projects are required that address or identify<sup>14</sup>:

- ◆ epidemiological and demographic regional variations including morbidity, mortality, treatment, risk factors, follow up and migratory patterns;
- ◆ barriers to access and management issues, including health service systems and structures; and
- ◆ various interventions focusing on risk factors and treatment to be trialled and evaluated using appropriate methodology.

Behavioural and sociological research was also supported as a priority and the participants called for funding bodies to alter their criteria and review processes and ensure that there is appropriate peer review by social and behavioural scientists to specifically support these categories of proposals.

With this solid evidence base further representation was made by RRAAC to the NHF Cardiovascular Health Advisory Committee (CVHAC), CVHAC controls the NHF research program. Associate Professor Ian Anderson and Professor Kerin O’Dea, as guests, and Professor Brian Oldenburg and Pat Field, as committee members, presented the findings of the previous 18 months work to the committee. The following recommendations were made:

- ◆ that \$275 000 is allocated from the NHF research budget to support appropriate research, and study grants, within specified criteria, for research in rural, remote

- and Aboriginal and Torres Strait Islander populations in the identified priority areas;
- ◆ that allocation of this money to be by
    - a call for submissions for appropriate research projects within the priority areas and specified criteria to a maximum level of \$250 000, and
    - scholarships or grants for Aboriginal and Torres Strait Islander students to study in a priority areas. The dollar value of the scholarships or grants to be matched by the hosting/supervising academic organisation. (total from NHF \$25 000). This would support two half PhD scholarships or several smaller study grants with the hosting organisation contributing an equal dollar amount;
  - ◆ that processes to be commenced in the year 2000 for projects and study programs in 2001 as follows
    - a separate call for submission of research proposals and application for study grants in the priority areas
    - specific criteria to be developed to assess the submissions
    - reviewers and research interview committee members with specific expertise in the priority areas are recruited
    - successful proposals and study grants are funded from the \$275 000 allocated from the research budget; and
  - ◆ that money is recurrent and the amount reviewed annually in line with other NHF budget procedures<sup>15</sup>.

## RESULTS

The proposal was supported in principle by the CVHAC. An ongoing process was determined to action the development of criteria and call for submissions and to decide on how the program should be link with the NHF mainstream research program.

Criteria was based on the National Health of Medical Research Council (NHMRC) criteria for research in Aboriginal and Torres Strait Islander populations, and included the need for research to be sustainable, involve the community, to be of benefit and transferable.

Following this decision, a request was made to DHAC for matched funding for this program. The branches of Population Health and the Office of Aboriginal and Torres Strait Islander have supported this request.

Submissions were called for in the identified priority areas and addressing the criteria early in August 2000. A two stage process has been instituted with a short expression of interest in the first instance and short listed applicants asked to develop full submissions. The NHF working group for this process recommended that money

should be allocated in amounts sufficiently large to enable researchers to carry out substantial work and reserved the right to only allocate one or two grants and to link applications if appropriate. The allocation of funding is still being determined.

The pool of funds is \$250 000, allocated by the NHF and \$250 000 from the DHAC. \$500 000 in total. The original amount requested was not fully met by the NHF and therefore the scholarship component of the program has not yet been funded. The other component of the proposal that to date has not been supported is the recommendation that funding should **“be recurrent and the amount reviewed annually in line with other NHF budget procedures.”** So far there has been a one off allocation of funds only. This will need to be addressed otherwise the gains made to date will be insignificant in view of the longer-term nature of the research questions and the high degree of need.

## CONCLUSION

Significant progress has been made with the achievement of the allocation of resources to an area of the highest research priority. The strength in the process has been the strong collaboration and teamwork with a team that represents a broad cross section of interests and expertise. It is also built on an old recipe that works, that is, gather the evidence to support your argument, lobby for support and involve the right people, keep up the pressure remembering the fine line between lobbying and harassment, and believe that it can be done.

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## AUTHORS

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Since joining the National Heart Foundation in January 1998 Patricia has been involved with developing strategies for rural and remote areas and Aboriginal peoples and Torres Strait Islanders across the spectrum of primary and secondary prevention and acute care.

Patricia's current activity include:

- ◆ developing co-ordinated strategic approaches to health service delivery that include health service providers, Commonwealth, State and Territory governments, non-government organisations, and academic institutions;
- ◆ developing alternative models of health service delivery in order to improve access to health services for all people; and
- ◆ developing research priorities, particularly in the areas of rural, remote, Aboriginal and Torres Strait Islander people.

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