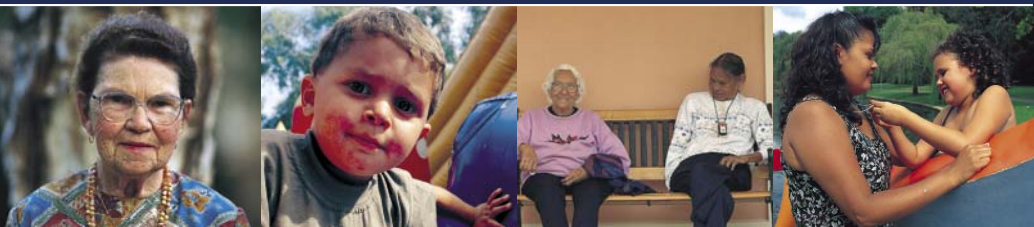




Australian Government
National Health and Medical Research Council

INVESTING IN AUSTRALIA'S HEALTH



The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health Through Research

The Aboriginal and Torres Strait Islander Research
Agenda Working Group (RAWG) of the NHMRC



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October 2002

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Please note: Following endorsement of this document by the National Health and Medical Research Council (NHMRC) in October 2002, and with the agreement of the Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG), the title of this document has been changed from ‘The RAWG Road Map: a strategic framework for Aboriginal and Torres Strait Islander health’ to ‘The NHMRC Road Map: a strategic framework for improving Aboriginal and Torres Strait Islander health through research.’

PREFACE

The National Health and Medical Research Council recognised the need to develop a cohesive and coordinated approach to address the health research needs of Aboriginal and Torres Strait Islander peoples. As a consequence, the Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG) was established as a joint undertaking between the NHMRC and OATSIH in 1997.

Early in 2001, the RAWG undertook to develop a 'Road Map' which would identify and codify agreed national research priorities in Aboriginal and Torres Strait Islander health.

The RAWG embarked on an extensive consultation process, which included a series of workshops to engage a broad range of stakeholders, including researchers, Aboriginal and Torres Strait Islander community representatives, community controlled health organisations, health care providers, policy makers, research funders and State and Territory government representatives, in the priority setting process. The purpose of the workshops were to obtain consensus on, and to refine, priority research questions from the broad themes for health research identified in the Road Map consultation document. In addition to the workshops a paper-based consultation was undertaken to enable coverage of a broader range of views from institutions and other organisations not represented at the workshops.

Two publications have been produced as a result of the above process:

- The NHMRC Road Map - A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research; and
- Report to the Aboriginal and Torres Strait Islander Working Group - Final Report of Community Consultations on the RAWG Road Map.

These documents are intended to complement each other. *The NHMRC Road Map - A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research* identifies six broad areas of need for discussion, and outlines the process to identify, and gain consensus on national priorities in Aboriginal and Torres Strait Islander health research. This document also incorporates outcomes derived from the consultation process.

The second document in the series, the *Report to the Aboriginal and Torres Strait Islander Working Group - Final Report of Community Consultations on the RAWG Road Map*, presents in more detail the outcomes of the Road Map consultations.

The RAWG Road Map was endorsed by NHMRC at the 144th session of Council in October 2002. The outcomes of the Road Map consultations will form the basis of the NHMRC's strategic plan to substantially increase its commitment and support for Aboriginal and Torres Strait Islander health research over the next triennium.

The NHMRC Road Map and the 'Outcomes of the Community Consultation on the RAWG Road Map' report are now available to inform all parties with an interest in Aboriginal and Torres Strait Islander health research.

THE ABORIGINAL AND TORRES STRAIT ISLANDER RESEARCH AGENDA WORKING GROUP (RAWG) ROAD MAP

INTRODUCTION

The National Health and Medical Research Council's major objective is to advise the Australian community on the achievement and maintenance of the highest practicable standards of individual and public health, and to foster research in the interests of improving those standards. The council currently fosters this objective through three primary programs – advice, ethics and research. Aboriginal and Torres Strait Islander peoples are a particular subgroup of the Australian community with significantly poorer health standards than other Australians.

Throughout the 2000-2003 triennium the NHMRC has fostered the development of the RAWG Road Map; a strategic framework for the development of a health research agenda which engages Aboriginal and Torres Strait Islander communities with researchers, health service delivery and policy makers. More than 250 people had direct input into the development of this framework through attendance at one of four workshops conducted in Perth, Darwin, Brisbane and Melbourne with representation from all States and Territories and a balance of Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander participants. Additional input was received from 23 organisations through submissions to the paper based consultation process. The overwhelming outcome of the consultation process was an endorsement of the directions and themes of the RAWG Road Map. This process of open consultation and vigorous debate has highlighted a number of areas where priority research should be developed as a matter of urgency, to complement existing researcher driven programs. In addition the workshops provided opportunity for participants to make constructive comment on process and ethical issues related to the conduct of Aboriginal and Torres Strait Islander health research.

SCOPE OF THE PROBLEM

The 2001 census showed that the Aboriginal and Torres Strait Islander population is estimated to be 460 140 people, comprising approximately 2.4% of the total Australian population. It would seem plausible that despite the wide geographic distribution and heterogeneity of Aboriginal and Torres Strait Islander communities, concerted national effort could result in substantial health gain for this relatively small subset of the total Australian population.

The poorer health standards which Aboriginal and Torres Strait Islander peoples' experience relative to other Australians are expressed in a significantly shorter average life expectancy at birth, higher rates of death, illness, injury and associated disability and compromised quality of life across all age and sex groupings.

Aboriginal and Torres Strait Islander peoples have a life expectancy at birth, which is some twenty years less than other Australians. Almost half (45%) the population of Aboriginal and Torres Strait Islander males die before age 45 years, and approximately 35% of Aboriginal and Torres Strait Islander women die before age 45 years. The major cause of excess deaths for Aboriginal and Torres Strait Islander peoples, compared to the total population,

is cardiovascular disease (31.2% of excess deaths). The other major causes of excess deaths are external causes, endocrine and metabolic diseases (primarily diabetes-related) and respiratory diseases. Aboriginal and Torres Strait Islander women experience poorer pregnancy outcomes and Aboriginal and Torres Strait Islander infants and young children also have higher death rates from predominantly preventable infections and accidents. Indigenous Australians have higher rates of illness, hospitalisation, disability and impaired quality of life. Social and emotional wellbeing / mental health inequalities are expressed in higher rates of mental illness, intentional injury and deaths from suicide more than twice the rate of other Australians. The major causes of hospital admissions are dialysis, injury and poisoning, respiratory diseases, digestive diseases, mental and behavioural disorders, and pregnancy and childbirth.

Communicable diseases across the spectrum, with the exclusion of some vaccine preventable conditions, are more prevalent in Aboriginal and Torres Strait Islander communities. HIV / AIDS incident rates are comparable to those of other Australians, but are stable whilst the rate for the general population peaked in 1994. A greater proportion of HIV / AIDS cases among Aboriginal and Torres Strait Islander peoples result from heterosexual contact and affect women. Poor oral health occurs more commonly among Aboriginal and Torres Strait Islander peoples and results in impaired quality of life from infection, pain and impaired eating. Aboriginal and Torres Strait Islander peoples experience higher rates of exposure to health risk through poor nutrition, cigarette smoking, inactivity, obesity, consumption of alcohol and illicit substances such as inhalants, heroin and cannabis, sexual health risk behaviours, and a range of other environmental factors, cultural dislocation, social and economic disadvantage.

ROLE OF THE NHMRC

The Australian Government and people have a commitment to improving the health of Aboriginal and Torres Strait Islander peoples. The achievement of this commitment requires concerted effort from researchers, health service providers, policy makers, state and commonwealth governments, the private sector and philanthropic organisations in partnership with Aboriginal and Torres Strait Islander communities. The National Health and Medical Research Council, has a role to play in the improvement of the health standards of Aboriginal and Torres Strait Islander peoples through comprehensive action at the level of each of its four principal committees, acting to:

- develop advice and guidelines on Aboriginal and Torres Strait Islander health issues;
- issue guidelines on ethical issues relating to human research involving Aboriginal and Torres Strait Islander peoples;
- award peer reviewed research grants of the highest attainable scientific quality which have the capacity to contribute to meaningful health gain for Aboriginal and Torres Strait Islander peoples; and
- conduct strategic commissioned research addressing areas of importance to Aboriginal and Torres Strait Islander peoples' health care, where research is currently underdeveloped, or there are gaps in the research effort.

Whilst the NHMRC has made some important direct and indirect contributions to this area in the past, the organisation is working to further refine and expand it's future contribution

to the national effort to improve the health standards of Aboriginal and Torres Strait Islander peoples. RAWG advocates the implementation of targeted strategic and cross NHMRC efforts toward the achievement and maintenance of the highest practicable standards of health for Aboriginal and Torres Strait Islander peoples throughout Australia.

The Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG) is a joint initiative of the Office for Aboriginal and Torres Strait Islander Health (OATSIH) and the National Health and Medical Research Council (NHMRC). RAWG was formed as a sub-Committee of the Strategic Research Development Committee (SRDC) in 1997 to identify Aboriginal and Torres Strait Islander health issues and research approaches that should be given priority for funding. RAWG's terms of reference are at Appendix A. The SRDC is a principal committee of the National Health and Medical Research Council.

On behalf of the communities it represents, and through a series of workshops and meetings, RAWG has developed a strategic framework for the processes necessary to identify Aboriginal and Torres Strait Islander health issues and the research approaches that should be given priority for funding. This framework is referred to as the 'Road Map'. The Road Map is a working document that identifies major themes for strategic priority driven research, and the necessary changes in the way research is supported, to address the existing knowledge gaps in Aboriginal and Torres Strait Islander health effectively. A diagrammatic representation of the Road Map is given at Appendix B.

This paper provides an overview of the Road Map. It is a living document that will evolve over time. Although details of the Road Map components may be modified in the process of consulting with stakeholders, the research themes it outlines and the principles underpinning these can be expected to remain relatively constant.

THE ROAD MAP

The overall objective of the RAWG Road Map is to support the NHMRC to *advise Aboriginal and Torres Strait Islander communities throughout Australia, on the achievement and maintenance of the highest practicable standards of individual and public health, and to foster research in the interests of improving those standards.*

RAWG has outlined six research themes critical to achieving substantial health gain for Aboriginal and Torres Strait Islander people:

1. Descriptive research which outlines patterns of health risk, disease and death. This information should be utilised to inform the development of sound preventive, early diagnosis and treatment based interventions which are likely to result in meaningful health gain for Aboriginal and Torres Strait Islander peoples.
2. A research focus on the factors and process that promote resilience and wellbeing; in particular but not exclusively, during the periods of pregnancy, infancy, childhood and adolescence and form the basis for good health throughout the lifespan.
3. A focus on health services research which describes the optimum means of delivering preventive, diagnostic and treatment based health services and interventions to Aboriginal and Torres Strait Islander peoples.
4. A focus on the association between health status and health gain and policy and programs that lie outside the direct influence of the health sector.

5. A focus on engaging with research and action in previously under-researched Aboriginal and Torres Strait Islander populations and communities.
6. Development of the nation's Aboriginal and Torres Strait Islander health research capacity (including training Aboriginal and Torres Strait Islander researchers) and health research practice in relation to Aboriginal and Torres Strait Islander communities.

These six theme areas are consistent with the functions which the National Health and Medical Research Council is charged with under the 1992 NHMRC Act:

- (a) to inquire into, issue guidelines on, and advise government and the community on matters relating to:
 - the improvement of health;
 - the prevention, diagnosis, and treatment of disease;
 - the provision of health care;
 - public health and medical research; and
 - ethical issues relating to health.
- (b) to advise and make recommendations to, the Commonwealth, the States and Territories on matters referred to in paragraph (a)
- (c) to make recommendations to the Commonwealth on expenditure:
 - on public health research and training;
 - on medical research and training;
 - including recommendations on the application of the Medical Research Endowment account; and
- (d) any functions incidental to any of the foregoing.

UNDERLYING PRINCIPLES

The Road Map and the research and development it advocates is underpinned by the following principles:

- Health being conceived of as "... not just the physical wellbeing of the body but a whole of life view, which embraces the life, death, life concept."
- Community involvement in the development, conduct and communication of the research.
- Communication of research plans, progress and results.
- Ethical research aiming to be of practical value to Aboriginal and Torres Strait Islander peoples and their service providers.
- Research support including the enhanced development of skills, knowledge and capacity in the Aboriginal and Torres Strait Islander research workforce.

- A focus on identifying ‘positive models’ or examples of success.

It is anticipated that such research and action spans all the possible explanations from the molecular to the population and health system level for poorer health standards among Aboriginal and Torres Strait Islander peoples and can contribute to health gain through:

- Understanding the foetal, infancy and childhood antecedents of adult morbidity and mortality.
- Basic molecular and genetic research.
- Epidemiology and demography.
- Social, cultural and behavioural contexts of ill health.
- Improved approaches for prevention, detection, diagnosing or treating disease and disability.
- Improved approaches to the systemic arrangements for the delivery of health care.

To effect improvements in health standards for Aboriginal and Torres Strait Islander peoples future research would be targeted toward the major causes and relevant risk factors for poorer health including chronic diseases (cardiovascular disease, renal disease, diabetes), injury (including accident prevention, assault, and suicide), mental health, communicable diseases (e.g. HIV / AIDS, hepatitis C, sexually transmissible disease), drug and alcohol misuse and maternal and child health. In addition to these core areas, there will be an array of health issues which are of particular importance to regional Aboriginal and Torres Strait Islander communities and which should be supported over time.

Whilst there is a requirement for ongoing consultation and review with Aboriginal and Torres Strait Islander people around the research processes and annual research priorities, some potentially beneficial research will continue to emanate from research driven processes. Funding allocations should have dedicated allocations for both community identified priorities and research driven research projects.

AGREEMENT-MAKING PROCESS RAWG 2000 – 2002 TRIENNIUM (or building partnerships through consultation)

The agreement-making process was a two-staged process leading to wider consultation seeking acceptance of the Road Map:

- RAWG initially sought NHMRC, ATSIC, NACCHO, AHMAC, SCATSIH and NATSIHC endorsement of the Road Map and its proposed processes.

Concurrently the following actions were undertaken during July to September 2002:

- Written comments were sought from a range of stakeholders (who may not have had the opportunity for comment during the workshop process) on the content of the RAWG Road Map (see Appendix C listing organisations who were invited to make comments on the Road Map).
- A series of workshops were attended by about 250 people, including researchers, Aboriginal and Torres Strait Islander communities and their representatives to refine the research issues outlined in each of the six key Road Map themes.

DESCRIPTION OF THE ROAD MAP THEMES

The Road Map describes a framework for processes that will result in priority research needs, questions and approaches being articulated and agreed on for six priority research themes. The research priority themes identified by RAWG in the Road Map address gaps in knowledge that need to be addressed so that sustainable strategies for improving health and promoting wellbeing can be developed. The key stakeholders of each research theme were instrumental in the development, agreement, investigation and communication of priority research questions to develop the theme. Specific priorities and objectives for strategic research and development of each theme identified in the Road Map were determined through stakeholder workshops, the details of which are published in a separate document.¹

Participants in the workshops emphasized the need to develop the Road Map with an emphasis on respect for culture and values; the links between research and the achievement of health gain and issues related to reform of the research enterprise in relation to Aboriginal and Torres Strait Islander health. These issues are outlined in a separate report on the Road Map consultation process.²

I. Descriptive research which outlines patterns of health risk, disease and death. This information should be utilised to inform the development of sound preventive, early diagnosis and treatment based interventions which are likely to result in meaningful health gain for Aboriginal and Torres Strait Islander peoples.

While reasonably current data on aspects of risk, disease and deaths in Aboriginal and Torres Strait Islander peoples is available, the quality in some areas remains inadequate. Strategies for health improvement require clarification of the role of social and other determinants of risk, disease and death. Research now needs to build on what is known about patterns of risk, disease and death and examine how interventions and systems can effect change in a sustainable manner.

Summary of issues arising from consultation process

The first order issue identified for this theme was to fully harness what is already known. There was a general view at the workshops that the knowledge is there to improve Aboriginal and Torres Strait Islander health, but is either inaccessible, inappropriate for individual communities or has not been translated into strategies that are practical. Focussing on what works, understanding why it works, and spreading the knowledge around was seen as critical.

At each workshop a similar range of suggestions emerged about how to harness current knowledge to improve health. Key strategies identified included:

- developing a community-endorsed research clearing house to summarise and promulgate the findings of national and international research to governments, researchers and communities;

¹ Refer 'Final Report of Community Consultations on the RAWG Road Map'. October 2002

² Refer 'Final Report of Community Consultations on the RAWG Road Map'. October 2002

- developing systems for secondary analysis and meta-analysis to identify critical success factors from interventions and programs;
- developing a coordinated national approach to data collection and data systems and improving community capacity to interact with data;
- developing data linkages able to monitor social and health inequalities in non-invasive ways, while addressing privacy and ownership issues; and
- using information from outside the health sector. The Report of the Royal Commission on Aboriginal Deaths in Custody and the Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families were seen as good examples.

The importance of conducting broadly based research that incorporated the non-health sectors was a particular emphasis of discussions under Road Map Theme One. It was thought that significant health gains could be achieved by developing interventions and strategies focussed on the interplay of health and non-health issues.

It was noted that there was considerable scope for accelerated research activity in this area. Cross-sectoral data linkage was a good starting point in identifying research gaps and areas of potential interest.

Draft research questions

- What are the critical success factors in the delivery of health services for Aboriginal and Torres Strait Islander peoples?
- What health benefits can be demonstrated by improving socio-economic conditions in Aboriginal and Torres Strait Islander communities?
- How can we link existing data, information, and research to ensure that results are of maximum benefit to the community?
- What are the databases that exist now and have existed in the past concerning Aboriginal and Torres Strait Islander health, what is the quality of the information that is held, and what needs to happen for available data to be used effectively?
- What are the successful data partnerships that are working well and can be described as best practice models for setting up other data linkage partnerships?
- How do we identify and address access to existing knowledge and information for communities, health professionals, and health workers at the community level?
- How can information be effectively shared between sectors (inside and outside health)?

Workshop participants expressed a view that the predominant place for descriptive research should be to fill gaps in existing knowledge. It was seen as important to take a long-term view through longitudinal studies and trend analysis. Some areas where descriptive research may be useful were identified, including:

- developing a better understanding of health across the life-course, including the causal pathways to disease, and critical points for interventions;

- developing an understanding of the diverse environments in which Aboriginal and Torres Strait Islander people live;
- considering clustering of health risk factors in Aboriginal and Torres Strait Islander communities;
- investigating the structural basis for health inequalities and the factors that impact on the way that services develop. It was noted that there is little to no information on the history of Aboriginal and Torres Strait Islander health and health care services in Australia;
- providing baseline data for evaluation purposes; and
- explaining causation, for example, access to care versus impact of behaviour in the public health field.

Descriptive research was seen as less important than intervention-based research except where there were information gaps to be filled. It was premature to identify these gaps until an audit of current research occurred.

2. A research focus on the factors and process that promote resilience and wellness; in particular but not exclusively, during the periods of pregnancy, infancy, childhood and adolescence and which form a basis for good health throughout the lifespan

There are two complimentary areas covered within this theme. The first is a focus on research around foetal development, infancy, childhood and adolescence and the factors which promote resilience and lay the foundations for good health throughout life. The second is a focus on research relating to quality of life and wellbeing throughout life. This may include oral health interventions, palliative care research, healthy ageing, mental health, disability and rehabilitation and family well being.

Summary of issues arising from the consultation process

Within this Road Map theme, an important area for research was developing an understanding, and disseminating positive examples, of resilience and strength in adversity. These examples should be gleaned by investigating a range of families and communities, guided by data from communities and from international experience.

‘Doing well’ in an Aboriginal and Torres Strait Islander context may mean something different than in the wider community. This needs to be better understood.

In considering resilience across the life-span, it was seen as important to identify the key transition points in peoples’ lives, whether these be age, life or community events, and the interventions that have proven most effective at different transition points. Aboriginal and Torres Strait Islander health workers were seen as important brokers and repositories of information in this regard.

Some transitions will present clearer opportunities for life changes than others, for example, young mothers having their first child may be more open to health advice than mothers having subsequent children. Other examples are the critical points during early life for the acquisition of language and other developmental milestones where intervention has

the capacity to make a greater difference to developmental outcomes. There needs to be a clearer understanding of the risk factors at different transition points, how to minimise risks or intervene to address negative impacts.

Finally, the importance of a 'whole of life', or life course approach was emphasised. The importance of viewing health disadvantage as a cumulative phenomena across life, and the need to intervene from the very early years, and in an ongoing manner to limit the severe health disadvantage which Aboriginal and Torres Strait Islander people face in the middle years of adult life was stressed in all four workshops. To achieve this requires a whole of government approach encompassing sectors outside health, and across the continuum of care. It was suggested that research funding bodies such as the NHMRC should broaden their representation to increase inter-sectoral and Aboriginal and Torres Strait Islander input.

Draft research questions

- What constitutes resilience, for individuals, families and communities, at particular stages of life?
- What are the contributing characteristics and perceptions of healthy Aboriginal and Torres Strait Islander families and communities about wellness? ; How do they vary from those in non-Aboriginal and Torres Strait Islander families and settings?
- At what points in the life cycle are interventions most effective?
- How do we maximise positive outcomes at times of transition?
- What life skills and knowledge enable communities to gain a sense of self-control and meaning in their lives?
- What is the relationship between trust, respect and cultural security, and how important is it to resilience and wellbeing?

3. A focus on health services research which describes the optimum means of delivering preventive, diagnostic and treatment based health services and interventions to Aboriginal and Torres Strait Islander peoples

This priority theme encompasses research that examines the effectiveness and efficiency of primary health care and related services recognising factors such as geographic location, community groups, service infrastructure, governance and service mix. This theme also involves a focus on specific major causes of death, illness and disability and the application of preventive, diagnostic and treatment based interventions and health services.

Research on effective population health measures would be encompassed by this theme. Many mainstream health programs have an Aboriginal and Torres Strait Islander focus yet, at present, there is little reliable data on the uptake of these programs by Aboriginal and Torres Strait Islander peoples' or of their effectiveness.

Summary of issues arising from the consultation process

A fundamental question posed under this theme was, ‘why has health investment and health services generally failed to improve health outcomes for Aboriginal and Torres Strait Islander peoples?’ It was noted that a major reason for this was that many factors impacting on health lay outside the health sector.

Reform of health services was sought at several levels. Research can contribute evidence to support and drive reform. Suggested areas for reform included:

- the way that political decisions and inter-governmental relations impact on health. Financing decisions, including allocation of funds, priority setting, and the relationship between investment, need and utilisation require understanding and action. The question was asked: ‘why is it that Aboriginal and Torres Strait Islander peoples’ receive significantly fewer health interventions than non-Aboriginal and Torres Strait Islander peoples when they are significantly sicker?’;
- generating evidence about the efficiency and effectiveness of health spending and how that relates to risk factors: ‘what are the best buys in Aboriginal and Torres Strait Islander health?’ This should provide a strong justification for increased investment in prevention and integrated primary care initiatives, rather than in the acute care sector;
- a broader framing of health services to encompass and complement programs in housing, education and justice in a primary care setting. Integrated approaches that cross agencies and programs are essential. To work, these need to sit in a community controlled setting. Research can provide information about what works and why;
- barriers to accessing health services: the reality of living in poverty, having a poor sense of identity, lacking emotional support, living with racism, experiencing incarceration and living with violence all operate as barriers to access; and
- health services themselves may pose risks to Aboriginal and Torres Strait Islander health. For many Aboriginal and Torres Strait Islander peoples, there are low levels of trust, particularly in interactions with mainstream health services. There needs to be understanding of what makes services effective and accessible, and the reasons why mainstream services often fail Aboriginal and Torres Strait Islander people. The focus should be on evaluating and improving health systems. A system of accrediting services as culturally safe should be considered.

Draft research questions

- What are the critical success factors in the delivery of health services for Aboriginal and Torres Strait Islander peoples?
- What makes mainstream services work for Aboriginal and Torres Strait Islander peoples? Why do mainstream institutions (hospitals, universities, research agencies) often fail Aboriginal and Torres Strait Islander peoples?

- How can services be designed and delivered that support core cultural values; what are the long term health benefits of delivering services in culturally appropriate ways and how does this compare to the cost of such delivery systems?
- Does the current system of allocating funding correspond to need?
- What factors shape the utilisation of primary health care services by Aboriginal and Torres Strait Islander peoples?
- What is the impact of Aboriginal Medical/Health Services and other community based service provision systems on health outcomes for communities: in an historical and contemporary context?

4. A focus on the association between health status and health gain and policy and programs that lie outside the direct influence of the health sector

International research, which has taken a broader approach to health status, has highlighted the impact of factors such as locus of control, lack of social capital and loss and grief on health status. Little research has been undertaken in this area in Australia. Associated with this is a need for greater understanding of environmental health. Other factors that may be the focus of research in this area include: food supply; education; employment and economic security; transport, personal and community safety and play, sport and recreation.

Summary of issues arising from the consultation process

It was acknowledged throughout the consultations that interventions outside health had the potential to deliver considerable health gain. There needs to be greater understanding of the priority areas outside health that can make a difference in local communities or geographic sectors. A range of areas were cited as requiring attention and understanding:

- the impact of poverty on health and what this means in an Aboriginal and Torres Strait Islander context. Aboriginal and Torres Strait Islander families face different socioeconomic pressures;
- the importance of access to appropriate education and employment opportunities in developing healthy individuals and communities. Educational opportunities were seen as pivotal in this regard, starting as early as pre-school interventions;
- how technology has impacted on health for many communities leading to physical inactivity and increased risk of cardiovascular disease and diabetes; and
- the fundamentals for a healthy environment and lifestyle that are missing from many communities, housing, clean water, sewerage, safe surroundings.

Defining social determinants of health in an Aboriginal and Torres Strait Islander context was an area for attention. It was noted that this may be different from general community definitions. There has been international work looking at the differences in social determinants of health across communities. Although there is some work being undertaken in Australia, it is not yet well developed.

The Report of the Royal Commission on Aboriginal Deaths in Custody and the Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from

their Families hold a wealth of information on the impact of factors outside health on health outcomes. This information should be made more accessible. Gaps in knowledge should be addressed, in the first instance by reviewing and linking health and non-health data.

The importance of intersectoral and multidisciplinary research collaborations was a recurring theme of the consultations. Models of successful intersectoral collaboration need to be developed and understood. Existing successful models should be investigated to identify critical success factors and findings disseminated. To achieve effective collaboration across sectors means breaking down 'silos' between government agencies and programs and will require commitment at the highest level through a whole of government approach.

Pathways to health, educational and psychological outcomes are similar and have complex interactions. Research built on multidisciplinary collaborations combining research, policy and practice are key to making a difference. Partnerships between researchers and policy makers must be encouraged.

Draft research questions

- How do we conduct successful intersectoral research; what do these partnerships look like, how do they operate, over what time; where does the leadership come from, who benefits?
- What can we learn from models of service provision to Aboriginal and Torres Strait Islander communities that cross sectors, both for those services that have existed long term or those that are new or under development?
- What are the effects of racism on health?
- What are the income and expenditure patterns of Aboriginal and Torres Strait Islander households and what are the key financial responsibilities Aboriginal and Torres Strait Islander families face?
- How do we map the impact of sectors outside health with health research at the local level?

5. A focus on engaging with research and action in previously under-researched Aboriginal and Torres Strait Islander populations and communities

Gaps remain in knowledge and understanding of the health issues of some Aboriginal and Torres Strait Islander populations and communities. For example, there is a paucity of information on the needs of urban communities; Torres Strait Islander communities; young adults and the elderly.

Priority needs to be given to research that produces data and knowledge critical for health gain in these populations or communities.

Summary of issues arising from the consultation process

To identify under-researched areas requires an audit of existing data and research considered side by side with community identified priorities. Common to many of the Road Map themes, it was thought the research focus should be multidisciplinary and intersectoral, with attention to positive interventions.

In the course of the consultations, a number of areas were identified as requiring urgent research attention:

- a focus on certain geographic populations : while it was accepted that some Aboriginal and Torres Strait Islander populations had been the subject of significant amounts of research, there were many others who had experienced none at all, and had identified their circumstances as requiring research attention

These populations could be located in rural or remote settings, but more often were Aboriginal and Torres Strait Islander peoples living in major cities and the urban periphery. The situations of these urban and urban fringe populations were identified as a significant research gap, especially considering that the largest concentrations of Aboriginal and Torres Strait Islander populations are located in urban settings;³

- mental health: it was noted that mental health in Aboriginal and Torres Strait Islander populations comprises only 1% of mental health research publications, and attracts only about 2% of mental health research funding. This is despite a high and growing incidence of mental health conditions among Aboriginal and Torres Strait Islander populations evidenced in high rates of imprisonment, hospital admissions for substance abuse, self harm and injury, and youth suicide. The impact of external factors on mental health outcomes such as living with racism and removal from family, needs to be mapped and understood;
- understanding and developing effective interventions and help-seeking behaviours particularly for young men at risk of suicide;
- understanding the changing place of men and masculinity in Aboriginal and Torres Strait Islander culture: many communities and families have lost their positive male role models due to imprisonment or premature death. The impact of this on boys needs to be better understood;
- addressing incidence of injury, violence, sexual assault and child abuse in Aboriginal and Torres Strait Islander communities; and
- understanding the cycle of incarceration and its impact on individuals and communities.

There was a view that research should move away from a fundamentally conservative agenda and practice and focus instead on breaking dysfunctional cycles in communities.

Draft research questions

- What are the coping strategies in an urban Aboriginal identity and urban Torres Strait Islander identity?
- What are the regional specific barriers to accessing health services?

³ The Australian Bureau of Statistics analysis of 2001 Census data, estimates that around 150,000 or more than a third of the total Aboriginal and Torres Strait Islander population lives across the 5 ATSI regions of Sydney, Brisbane, Coffs Harbour, Wagga Wagga and Perth, cited in 'Australian Bureau of Statistics Media Release: 4705.0 2001 Census: Further Analysis of Aboriginal and Torres Strait Islander population distribution', June 2002.

- What are the specific issues in accessing health services in peri-urban areas, and what is the ability of those services to change in response to rapid changes in demographics?
- How is maleness/masculinity defined in Aboriginal and Torres Strait Islander communities, and what are the implications for health and wellbeing?
- What are the issues in the cycle of incarceration experienced by many individuals and communities: before, during and after prison?
- What is the prevalence and incidence of specific health conditions across various settings, geographic areas, age gaps etc?
- How is violence defined and perceived by Aboriginal and Torres Strait Islander communities, and how will researchers use information about violence in communities?
- How can communities be helped to build the capacity to respond effectively to the mental health issues they face?

6. Development of the nation's Aboriginal and Torres Strait Islander health research capacity (including training Aboriginal and Torres Strait Islander researchers) and health research practice in relation to Aboriginal and Torres Strait Islander communities

This theme includes a focus on the range of options for building the pool and skill base of Aboriginal and Torres Strait Islander health researchers. It also encompasses the development of consultation and research practice protocols including ethical guidelines and specifying the need for mechanisms for disseminating and implementing research outcomes to be addressed as part of standard research practice and to be factored into the funding mechanisms for health research. It also includes a focus on the development and testing of better research tools and treatment methodologies, for example research into measurement and treatment of mental health in Aboriginal and Torres Strait Islander communities. Optimal methods for the dissemination and implementation of research outcomes are also included in this theme.

Summary of issues arising from the consultation process

The development of capacity was described at several levels. At the level of an individual community, any research must develop that community's capacity and infrastructure, both through enabling and supporting community participation and management of the research process and enabling sustainable implementation of findings. The inclusion of effective capacity building strategies should be a mandatory prerequisite for NHMRC-funded research that addresses Aboriginal and Torres Strait Islander issues. Broad agreement on this requirement among other research funding bodies and government agencies should be sought.

Working with communities to build capacity and conduct research requires strong partnerships, based on cultural respect, to be formed between communities and academic/research bodies. There are many examples of partnerships between hospitals and research bodies in the biomedical field; the same types of relationships need to be developed between research bodies, the community-controlled sector and individual communities.

Secondly, at the macro level, there must be concerted effort to build an Aboriginal and Torres Strait Islander research workforce. This requires collaboration by governments and communities to develop effective capacity building strategies, followed by planned investment by government and education sectors, focusing on positive models drawn from Australia and internationally. Strategies should address:

- innovative training and education models;
- career pathways;
- the availability and quality of education at all levels, pre-school, primary, secondary and tertiary; and
- role and experience of Aboriginal and Torres Strait Islander peoples in the health workforce.

While it was recognised that developing Aboriginal and Torres Strait Islander capacity was paramount, it was also seen as crucial:

- to build robust partnerships between Aboriginal and Torres Strait Islander peoples and non-Aboriginal and Torres Strait Islander partners founded on community priority setting and cultural respect; and
- to develop a high quality non-Aboriginal and Torres Strait Islander research workforce with the skills, values and experience to function as proper research partners.

Finally, at a workforce level, there is a need to better understand workforce supply, both for researchers and Aboriginal and Torres Strait Islander peoples in the health workforce who should be skilled in research techniques and will be central to implementing findings and delivering interventions. Workforce modelling and composition studies will inform us about workforce gaps and support long-term workforce planning.

Draft research questions

- How do we ensure that Aboriginal and Torres Strait Islander workforce planning is responsive to current and future community need?
- How do we increase the Aboriginal and Torres Strait Islander workforce in high profile management, research, service delivery and policy areas?
- What are the characteristics of a successful Aboriginal and Torres Strait Islander researcher?

⁴ Refer 'Final Report of Community Consultations on the RAWG Road Map', October 2002

IDENTIFYING PRIORITY RESEARCH

As well as identifying research issues and broad questions throughout the RAWG consultation process, participants reflected, toward the end of the individual workshops, on the factors that influenced their prioritisation of particular issues and questions.

The factors identified as important in setting priorities generally align with the Road Map themes and areas for general attention presented at Sections 5.1 – 5.3 of the report on the RAWG workshops⁴.

Across the four workshops, the key reasons for assigning a higher priority to specific research questions were that it:

- could make a difference to Aboriginal and Torres Strait Islander health, as defined by Aboriginal and Torres Strait Islander people;
- addressed research gaps and high priority areas, particularly a focus on culture and identity;
- could improve a community through capacity building, empowerment, and research transfer;
- addressed social determinants of health and forged integrated, cross-sectoral partnerships;
- took a multidisciplinary, holistic approach; and
- posed a ‘researchable’ question: it was noted that researchers had an ethical responsibility to ensure questions are valid.

This information is relevant to RAWG in further developing an Aboriginal and Torres Strait Islander health research agenda, as it gives an insight into the factors that the community sees as important in choosing between research initiatives.

IMPLEMENTATION

Objectives identified through stakeholder workshops will be achieved through strategic partnerships and agreements between: communities and their representatives; research funders; policy makers; research institutions; education institutions and other organisations whose activities impact on health. It is envisaged that implementing the Road Map will involve:

- Regular consultation and negotiations with a wide range of stakeholders.
- A long term workplan that extends beyond the current NHMRC triennium and is regularly reviewed, and an adequate budget to undertake the work envisaged.
- The positioning of RAWG, or its new incarnation within NHMRC in a way that enables the most efficient and effective implementation of the Road Map.
- The commissioning of an independent review at the end of the next two trienna to evaluate the efficacy of RAWG and the Road Map as mechanisms for the strategic development of Aboriginal and Torres Strait Islander health research.

In implementing the Road Map, RAWG aims to:

- Encourage the development of a research environment conducive to the evolution of an effective Aboriginal and Torres Strait Islander health research field. This will be achieved through consultation and input from key research funders within and outside the NHMRC and the development of strategic partnerships.
- Develop links between service providers, researchers and policy makers to:
 - increase capacity for training and mentoring opportunities for Aboriginal and Torres Strait Islander researchers;
 - develop a positive experience of research in Aboriginal and Torres Strait Islander communities;
 - implement standards for ethical research; and
 - develop co-operative funding agreements.

REVIEW

It is intended that progress in implementing the Road Map principles and priorities will be monitored and reviewed on a regular basis. This will help to inform future policy and the direction of new research.

Measures of the impact of the Road Map on the development of the research field may include increases in:

- the number of Aboriginal and Torres Strait Islander peoples who are research scholarship holders, research technicians and service interns;
- an increase in the number of priority and researcher driven projects funded out of NHMRC which are of the highest attainable scientific standards and have the capacity to contribute to meaningful health gain for Aboriginal and Torres Strait Islander peoples;
- improved mechanisms within the NHMRC for monitoring and evaluating Aboriginal and Torres Strait Islander health research activities and support;
- the number of communities that report positive outcomes as a result of their involvement in research;
- the growth and strengthening of Aboriginal and Torres Strait Islander research networks, especially those involved in health research; and
- The number of organisations that have endorsed and adopted the Road Map principles and priorities will reflect the effectiveness of the Road Map.

The effectiveness of RAWG will be assessed by the extent of progress against its Terms of Reference.

TIMELINE

The implementation of the Road Map should start immediately, but extend beyond the current RAWG triennium (2000-2003). The rate of progress and achievement of objectives may not be easily predicted at this early stage. Good outcomes will require sound partnerships and secure agreements and these take time. The NHMRC has made a significant commitment to improving Aboriginal and Torres Strait Islander health research through the establishment of RAWG. It is important that the commitment to RAWG and implementation of the Road Map continue in the next NHMRC triennium.

APPENDIX A

ABORIGINAL AND TORRES STRAIT ISLANDER RESEARCH AGENDA WORKING GROUP (RAWG)

Terms of Reference

1. Identify Aboriginal and Torres Strait Islander health issues and research approaches that should be given priority for funding by:
 - a. determining and implementing priority setting mechanisms for Aboriginal and Torres Strait Islander health which are consistent with the principles for Indigenous health research developed by RAWG and endorsed by SRDC;
 - b. enabling Aboriginal and Torres Strait Islander involvement through their representative bodies and individuals with specific expertise in priority setting processes; and
 - c. considering ways to strengthen capacity at the community and primary health care levels for Aboriginal and Torres Strait Islander peoples to undertake research.
2. Establish SRDC endorsement and Ministerial approval of identified research priorities and approaches for Aboriginal and Torres Strait Islander health research:
 - a. establish a formal dissemination structure to have the identified research priorities taken into account in the research strategies for, and funding decisions of, other areas of the ONHMRC and the Department of Health and Aged Care; and
 - b. actively disseminate these priorities to stakeholders including other levels of government, the health sector, research institutions and health research training organisations, private sector research funders, the philanthropic sector and Aboriginal and Torres Strait Islander communities.
3. Establish RAWG as a mechanism for:
 - a. the provision of advice to other funding forums within the NHMRC and the Department on the design and process of funding rounds and the evaluation of applications for Aboriginal and Torres Strait Islander health research;
 - b. the provision of advice regarding priority areas for research in Aboriginal and Torres Strait Islander health; and
 - c. assessment of the Indigenous Health Research Criteria for research proposals submitted to SRDC (those which involve Aboriginal and Torres Strait Islander peoples and communities).
4. Establish funding requirements for Aboriginal and Torres Strait Islander health research that produces acceptable direct or indirect, sustainable and transferable health outcomes.

APPENDIX C

LIST OF ORGANISATIONS FOR PAPER BASED CONSULTATION

(Organisations who provided a response have been highlighted in bold)

Aboriginal and Torres Strait Islander Advisory Board

Aboriginal and Torres Strait Islander Commission

Aboriginal Health and Medical Research Council of NSW

Aboriginal Medical Service, Redfern

ACT Aboriginal and Torres Strait Islander Forum

ACT Department of Health and Community Care

Australian Chronic Diseases Prevention Alliance

Australian College of Health Service Executives

Australian Divisions of General Practice

Australian Indigenous Doctors Association

Australian Institute of Aboriginal and Torres Strait Islander Studies

Australian Institute of Health and Welfare

Australian Kidney Foundation

Australian Medical Association

Australian National University

Australian Research Council

Australian Rural Health Education Network

Australian Vice-Chancellors' Committee

Broken Hill University Department of Rural Health

Centre for Rural and Remote Health

Combined Universities Centre for Rural and Remote Health

Commonwealth Department of Education, Science and Training

Commonwealth Department of Family and Community Services

Commonwealth Department of Health and Ageing

Congress of Aboriginal and Torres Strait Islander Nurses

Cooperative Research Centre for Aboriginal and Tropical Health

Curtin University

Danila Dilba Aboriginal Medical Service

Department of Health and Community Services, NT

Department of Health and Human Services, TAS

Department of Health, WA

Department of Human Services, SA

Department of Human Services, VIC

Edith Cowan University

Enhealth Council

Flinders University

Health Advisory Council, National Health and Medical Research Council

Health Department of WA

Health Inequalities Research Collaboration, Sydney University

Indigenous Australians Sexual Health Committee

Indigenous Health Research Program, QLD Institute of Medical Research

James Cook University

La Trobe University

Menzies School of Health Research

Monash University

National Aboriginal and Community Controlled Health Organisation

National Aboriginal and Torres Strait Islander Health Council

National Health and Medical Research Council Principal Committees

National Heart Foundation of Australia

National Indigenous Environment Health Forum

National Secretariat of Torres Strait Islander Organisations

NSW Aboriginal Health Forum

NSW Health Department

NT Aboriginal Health Forum

NT Aboriginal Medical Services

NT Health and Community Services

NT University

Nunukuwarrin Yunti

Office of Aboriginal and Torres Strait Islander Health

QLD Aboriginal and Torres Strait Islander Health Forum

QLD Department of Health

QLD Institute of Medical Research

QLD University of Technology

RMIT University

Royal Australian College of General Practitioners

Royal Australian College of Nursing

SA Aboriginal Health Forum

SA Centre for Rural and Remote Health

St Vincent's Institute of Medical Research

Standing Committee on Aboriginal and Torres Strait Islander Health

TAS Aboriginal Centre
TAS Aboriginal Health Forum
TAS Department of Health and Human Services
Torres Strait Islander Advisory Board
Torres Strait Islander Health Forum
Townsville Aboriginal and Islander Health Service
TVW Telethon Institute of Child Health Research
University Department of Rural Health, Alice Springs
University of Melbourne
University of QLD
University of SA
University of Technology, Sydney
University of WA
University of Wollongong
VIC Aboriginal Community Controlled Health Organisation
VIC Aboriginal Health Service
VIC Advisory Council on Koori Health
VicHealth Koori Health Research and Community Development Unit
WA Aboriginal Community Controlled Organisation
WA Aboriginal Health Forum
Winnunga Nimmityjah Aboriginal Health Clinic and Health Service (ACT) Inc