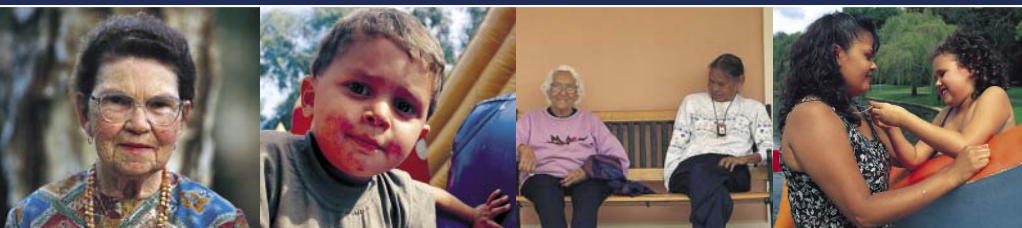




Australian Government

National Health and Medical Research Council

INVESTING IN AUSTRALIA'S HEALTH



Final Report of Community Consultations on the NHMRC Road Map

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



Australian Government

National Health and Medical Research Council

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October 2002

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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.

I EXECUTIVE SUMMARY

This is a report to the Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG) on the outcomes of consultations on the RAWG Road Map: A Strategic Framework for Aboriginal and Torres Strait Islander Health Research.

Consultation on the Road Map has been underway since late July 2002 and has comprised four Workshops and a process for written feedback.

The consultation has been highly successful, both in terms of the numbers, organisational links and expertise of those who participated, and in the quality of findings.

Over 200 individuals attended the four Workshops. People representing Aboriginal and Torres Strait Islander communities and organisations attended the Workshops in greater numbers than any other group. In addition, written submissions from 19 organisations were received.

I.1. SUMMARY OF FINDINGS

The overwhelming outcome of the consultation process was an endorsement of the directions and themes of the RAWG Road Map.

Written submissions identified the Road Map as a “...valuable contribution to the process of identifying priority research issues”, “a clear enunciation of research principles”, and an “...exceptional outcome which clearly, neatly and concisely captures virtually all the desirable attributes which might be sought in health service/public health research.”

The consultation encouraged debate and investigation in the broad area of Aboriginal and Torres Strait Islander health research. Though the information emerging from the Workshops and through written feedback was wide-ranging, the main findings grouped back to the six themes enunciated in the original Road Map document.

Several areas raised during the consultation were of such importance as to warrant special attention. Workshop participants agreed that an Aboriginal and Torres Strait Islander health research agenda should:

- put Aboriginal and Torres Strait Islander culture and values at its centre by:
 - focusing on how culture impacts on the resilience and wellness of individuals and communities, and
 - embracing self-determination and cultural respect as part of the research endeavour;
- focus on improving health outcomes for Aboriginal and Torres Strait Islander peoples. While the role of descriptive research was recognised and supported, there was a clear message that intervention research, looking at practical ways to improve health, needed particular attention;
- develop a research enterprise that supports community initiation and participation in research, capacity building, and sustainable, transferable outcomes.

In addition, the consultation process raised specific issues for attention under each of the six Road Map themes. Participants generally stressed the need for positively focussed research that identified and promulgated critical successful factors, and looked to achieve full benefit from the range of information (data, research, programs) that was already available.

The importance of understanding social determinants of health from an Aboriginal and Torres Strait Islander perspective, and conducting research of a multidisciplinary and cross-sectoral nature was stressed.

The consultation Workshops were asked to frame and prioritise broad research questions. Across the four Workshops, over 200 questions were generated. With some refinement, there are many strategic questions that have been framed through the Workshop process that warrant serious consideration as part of a future research agenda.

1.2. RESPONSE TO CONSULTATION OUTCOMES

The next step for RAWG is to determine an appropriate response and plan of action to take forward consultation outcomes.

Section 6 of this report addresses implementation issues.

In summary, it is recommended that:

- the NHMRC is informed of the RAWG consultation process and outcomes, and a recommended plan of action is submitted to the NHMRC for endorsement;
- minor redrafting of the RAWG Road Map occurs to reflect consultation outcomes, including the incorporation of refined research questions under each theme;
- consultation outcomes, together with an action plan is distributed to Workshop participants;
- stakeholders are informed of the Road Map and its implications;
- Road Map performance indicators are developed;
- the Road Map is implemented through the NHMRC, governments and other research funding agencies. Any changes to NHMRC structures and processes in the next triennium should reflect a commitment to, and monitoring of, Road Map implementation;
- a review of research gaps, and existing knowledge is facilitated;
- annual feedback and priority setting processes are put in place to enable regular review and refinement of the Road Map.

2. PURPOSE

This Report summarises the outcomes of consultations on the Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG) Road Map: A Strategic Framework for Aboriginal and Torres Strait Islander Health Research.

The Report makes recommendations for refinement and implementation of the RAWG Road Map and describes the implications for key stakeholders. The Report aims to:

- provide accessible information on the outcomes of the RAWG consultation process;
- identify priority research themes and ‘researchable’ questions for Aboriginal and Torres Strait Islander health that have emerged from the consultation;
- identify a process of implementation of an Aboriginal and Torres Strait Islander health research agenda for consideration by RAWG; and
- provide an historical record of the RAWG consultation through the detailed reports of each Workshop and written submissions, attached at Appendices One to Five.

3 RESEARCH AGENDA WORKING GROUP

3.1. STRUCTURE AND RESPONSIBILITIES

The Aboriginal and Torres Strait Islander Research Agenda Working Group is a sub-committee of the Strategic Research Development Committee of the National Health and Medical Research Council (NHMRC), and is jointly supported through the NHMRC and the Office of Aboriginal and Torres Strait Islander Health.

RAWG's focus is to achieve health gain for Aboriginal and Torres Strait Islander peoples by implementing, through research funding organisations and government agencies, a targeted and intervention-focussed research agenda able to produce sustainable and transferable health outcomes.

RAWG has advised the NHMRC in this and the preceding triennium on funding priorities, contextual issues and processes for Aboriginal and Torres Strait Islander health research.

3.2. THE RAWG ROAD MAP

In the current NHMRC triennium (2000-2003), RAWG has developed a strategic framework for Aboriginal and Torres Strait Islander health research, the 'RAWG Road Map'.

The purpose of the 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 interest of improving those standards".

The Road Map is underpinned by several principles:

- health being conceived through a whole of life view, not just as the physical wellbeing of the body;
- ethical research that embraces community involvement in the research process, communication of research plans, and a practical research focus; and
- research support that enhances skills, knowledge and capacity of an Aboriginal and Torres Strait Islander research workforce.

The Road Map proposes the development of six research themes essential to achieving health gain for Aboriginal and Torres Strait Islander peoples. In summary, these themes encompass:

1. Descriptive research which outlines patterns of health risk, disease and death;
2. Factors and processes that promote resilience and wellbeing across the lifespan;
3. Health services research that supports optimal delivery of services to Aboriginal and Torres Strait Islander peoples;

4. The association between health status and health gain and programs outside health;
5. Engaging with research and action in previously under-researched communities; and
6. Developing Aboriginal and Torres Strait Islander health research capacity and practice.

3.3. CONSULTATION ON THE ROAD MAP

RAWG has been conducting thorough consultation on the Road Map document, inviting written feedback and convening a series of workshops.

3.3.1 Workshops

Four workshops have been held across Australia, in Perth, Darwin, Brisbane and Melbourne. Detailed reports on each Workshop are at Appendices One to Four.

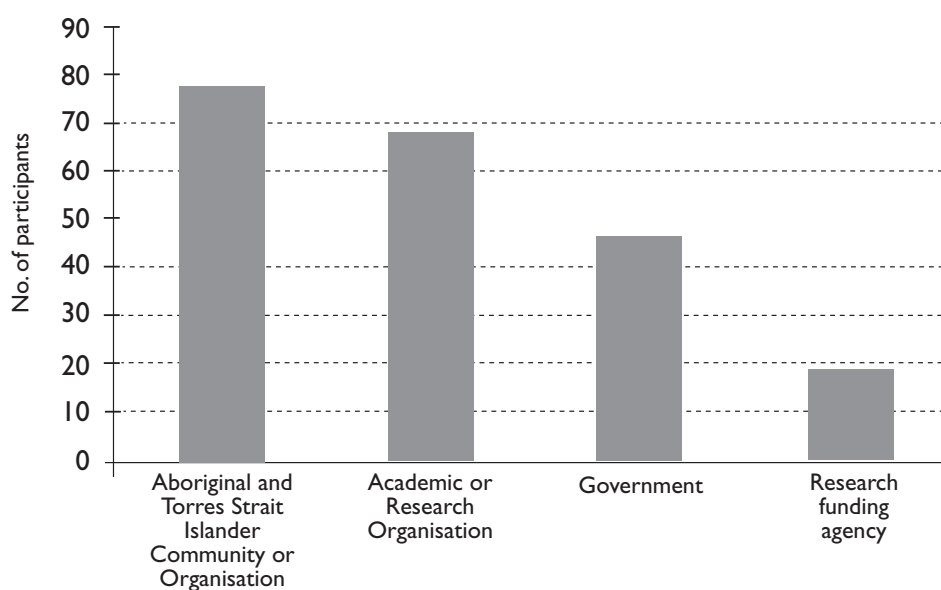
Invitations to the Workshops were extended to representatives and individuals from Aboriginal and Torres Strait Islander communities and organisations, research and academic institutions, research funding agencies and governments.

RAWG sponsored the attendance of 18% of participants by meeting travel and accommodation costs, primarily for those travelling from Aboriginal communities and organisations. Many Aboriginal and Torres Strait Islander participants did not require assistance with costs as they resided in the city where the workshop was being held, or were representing an organisation that met their costs.

211 individuals attended the Workshops with roughly equal representation of Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander people. Representation from all States and Territories was achieved.

Figure 1 distributes Workshop participants across the four main categories represented at the Workshops. The largest number of participants represented Aboriginal communities or organisations¹ (37%) followed by representatives of research and academic institutions (33%), government (22%) and the NHMRC and its committees (9%).

¹ Included in this figure are representatives of research organisations that have a specific Aboriginal and Torres Strait Islander focus such as the Cooperative Research Centre for Aboriginal and Tropical Health. Members of RAWG are listed under research funding agency

Figure 1: Primary organisation represented by participants in the RAWG workshops

Each Workshop was hosted by a research organisation. The host organisations provided administrative and organisational support, introductory speakers and contributed materials and resources, crucial to the Workshop's success. Table 1 details Workshop dates, host organisations and the specific Road Map themes considered.

Table 1: Host organisations

Venue and date (2002)	Host organisation	Road Map Themes
Perth 29—30 July	Telethon Institute for Child Health Research and Curtin University	2, 4, 5, 6
Darwin 12—13 August	Menzies School of Health Research and the Cooperative Research Centre for Aboriginal and Tropical Health	1, 4, 5, 6
Brisbane 26—27 August	University of Queensland and James Cook University	1, 4, 5, 6
Melbourne 9—10 September	VicHealth Koori Health Research and Community Development Unit, University of Melbourne	3, 4, 5, 6

3.3.2 Workshop approach

To support comparability of outcome and achieve RAWG's stated objectives for the Workshops, consistent methodology and facilitation² was used. Each Workshop was guided through three exercises:

- Firstly, the broad range of research areas and related issues relevant to the designated Road Map Themes were identified and organised into groupings;
- Secondly, a detailed analysis of each grouping occurred against the four areas identified by RAWG as desired Workshop outputs:
 - the knowledge needed to further develop the identified issue or issues
 - areas where research may provide the knowledge needed;
 - broad research questions that may address identified knowledge gaps;
 - opportunities and barriers to the development of strategic research; and
 - finally, priority research questions and areas were identified through the allocation of rankings and (nominal) research dollars.

3.3.3 Written submissions

In addition to the Workshops, the draft RAWG Road Map was circulated to agencies with an interest in Aboriginal and Torres Strait Islander health, research and education. Comments were sought on any weaknesses with the Road Map's approach, areas of achievement, and important research questions or issues to be addressed in the context of the Road Map.

24 written submissions were received from 19 organisations. A full report on the results of written feedback is at Appendix Five.

The remainder of this report:

- provides information on the historical context in which RAWG consultations have occurred;
- summarises consultation findings that have emerged from the four workshops and from written feedback; and
- recommends a course of action for RAWG in responding to consultation findings, including evaluation and monitoring arrangements.

² Mr Shane Houston facilitated the four workshops. Ms Rosemary Huxtable from Focal Point Consulting provided administrative and rapporteur services and prepared reports.

4. HISTORICAL CONTEXT

Consultations on the RAWG Road Map have occurred within the context of continuing poor health of Aboriginal and Torres Strait Islander populations and a heightened interest on the part of research funding agencies on priority focussed research.

4.1. ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH

The 2001 Census estimated the resident Aboriginal and Torres Strait Islander population of Australia at 460,140 comprising 2.4 % of the total population.

There remains significant evidence of poor health standards, increased morbidity and mortality and clustering of health risk factors in Aboriginal and Torres Strait Islander populations³. Aboriginal and Torres Strait Islander peoples:

- have a life expectancy at birth, which is twenty years less than other Australians - 45% of males and 35% of females die before the age of 45 years;
- are more likely to smoke, consume alcohol at hazardous levels, be exposed to violence and be categorised as obese, all of which comprise significant risks to health;
- are more than twice as likely to have babies of low birth-weight or who die at birth or in the early post-natal phase and three to four times more likely to have children who die in early childhood generally from preventable causes such as infection or injury;
- experience higher rates of hospitalisation for most diseases and conditions, particularly for care involving dialysis, injury and poisoning, respiratory disease, digestive disorders and mental and behavioural disorders;
- suffer from higher levels of mental and behavioural disorders: there are many more hospital separations among Aboriginal and Torres Strait Islander people resulting from psychoactive drug use, intentional injury and assault than would be expected from population data as well as elevated rates of youth suicide;
- experience lower rates of literacy and numeracy among children, and do not progress to Year 12 and beyond at anywhere near the same rate as the non-Aboriginal and Torres Strait Islander population;
- are more likely to be imprisoned - 19% of the adult prison population and 41% of the juvenile correction population are Aboriginal and Torres Strait Islander; and
- experience higher rates of unemployment, particularly among the young, and a lower combined household income despite there being on average more residents per household.

³ Evidence cited in this section is drawn from two publications:
 Eades, S J (2001), "The RAWG Research Road Map Background Paper: Maternal Health, Infancy, Childhood and Adolescent Focused Research, Laying the Foundations for a Lifetime of Health for Aboriginal and Torres Strait Islander People"
 Australian Bureau of Statistics & Australian Institute of Health and Welfare publication, "The Health and Welfare of Aboriginal and Torres Strait Islander Peoples 2001"

4.2. RESEARCH ENVIRONMENT

4.2.1 Role of NHMRC

The NHMRC consolidates the dual functions of research funding and development of advice. The statutory role of the NHMRC is to:

- raise the standard of individual and public health throughout Australia;
- foster development of consistent health standards between the various States and Territories;
- foster medical research and training and public health research and training throughout Australia; and
- foster consideration of ethical issues relating to health.

Since 1997, the NHMRC has set aside funding to develop strategic capability in areas where the research effort is not commensurate with the magnitude of its importance to health care in Australia. Aboriginal and Torres Strait Islander populations are recognised by the NHMRC as the most disadvantaged group in Australia.

In light of the indicators of health status cited at Section 4.1, the NHMRC acknowledges that health research in this area has not contributed in a significant or systematic way to improved health outcomes for Aboriginal and Torres Strait Islander populations.

4.2.2 Historical developments

Several reviews and consultative processes in recent years have lent weight to an increased role for ethically conducted research in achieving Aboriginal and Torres Strait health gain:

- the Strategic Review of Health and Medical Research (the Wills Review) conducted in 1998 recommended, as a matter of urgency, the development of priority-driven research that contributes directly to population health and evidence-based health care; and
- the House of Representatives Standing Committee on Family and Community Affairs 'Health in Life' Report released in May 2000 recommended that the NHMRC allocate at least 5% of total annual research funding to Aboriginal and Torres Strait Islander health research, developed with the Aboriginal and Torres Strait Islander community and aimed at improving health.

Putting in place structures and processes to improve the research effort directed at Aboriginal and Torres Strait health has been a priority for action by the NHMRC in recent years. Several initiatives have been put in place:

- the Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG) was formed in 1997 to take a lead role in establishing the framework for strategic research for Aboriginal and Torres Strait Islander health gain, defined collaboratively with Aboriginal and Torres Strait Islander communities and organisations. The majority

of RAWG members are Aboriginal or Torres Strait Islander. A full list of members is at Attachment One to this report;

- the Indigenous Health Research Panel (IHRP) was established in 1999 to review Project Grant applications and ensure the applicants have adequately addressed the principles of ‘community participation, sustainability and transferability’. Reports from IHRP inform consideration of the scientific merit of proposals and has enabled grant reviewers to be better informed of the importance of Aboriginal health research, and the sensitivities and requirements of research in that field. There is expected to be a doubling of Aboriginal and Torres Strait Islander focussed project grants in 2003 compared to 2002; and
- the Australian Health Ethics Committee of the NHMRC is conducting a review of guidelines on ethical matters in Aboriginal and Torres Strait Islander health research. At the core of proposed changes is the principle that ethical practice should centre on Aboriginal and Torres Strait Islander values and address the core issues of reciprocity, respect, equality, survival and protection, responsibility, spirit and integrity.

4.2.3 National research review

The NHMRC is not alone in its efforts to progress strategic research issues. A broader process is occurring, involving research, scientific, business and the general community, to develop national research priorities. This process, coordinated through the Commonwealth Department of Education, Science and Training aims to:

- identify and address areas of strength, opportunity or need where an increase in research effort would make a significant contribution to national wealth and/or wellbeing; and
- determine what shift in research effort is needed, what new or improved research activities are required and how the targeting of research effort can best be achieved⁴.

There are strong similarities between this general process and the issues raised in the RAWG Road Map. In particular there is a shared focus on delivering measurable and significant positive impacts through high quality research; building capacity by developing expertise, infrastructure and collaborations and capturing the benefits of research.

⁴ Department of Science, Education and Training (2002), ‘Developing National research Priorities: An Issues Paper’

5. CONSULTATION OUTCOMES

This Section draws out the key findings of the RAWG consultation, across the four workshops and written submissions. The major themes for an Aboriginal and Torres Strait Islander health research agenda, the issues that should be addressed by each theme, and broad research questions are identified.

5.1. REFLECTIONS ON THE PAST

While the focus of the RAWG consultations has been on the RAWG Road Map and its themes, important contextual information emerged in the consultations about the perceived state of research into Aboriginal and Torres Strait Islander health and the impact of past experience on community attitudes toward research. This information provides a useful starting point for building reforms to research processes and priorities.

Many Workshop participants expressed disillusionment and dissatisfaction about the way in which research has been conducted in the past. Research was described by some as being too focussed on the priorities and career objectives of researchers rather than the priorities of communities, as at times irrelevant and non-inclusive, and as not contributing sufficiently to health improvements.

The way in which research was funded was seen as an impediment to successful partnerships and health gains for Aboriginal and Torres Strait Islander communities. It was argued that there is insufficient time or funding for researchers to undertake proper consultation with communities or build relationships of respect.

At the same time, Workshop participants also reflected on the positive developments in recent years, in the field of Aboriginal and Torres Strait Islander health research. Strong support was expressed for the emergence of soundly based partnership models that brought together representatives of Aboriginal communities, government and high quality research institutions, to implement a community defined, health research agenda.

The increasing acknowledgment in mainstream research and science of the importance of a ‘whole of life’ approach, a broader definition of health embracing social determinants and the place of culture, and use of qualitative methods was seen as aligning more closely to an Aboriginal and Torres Strait Islander world view.

The progress that had been made through RAWG and NHMRC consultations in recent years was commended. The development of the Darwin Criteria⁵ in 1998 was seen as a critical launching pad for change in the field. Many participants expressed optimism for the future of Aboriginal and Torres Strait Islander health research.

⁵ The ‘Darwin Criteria’ were developed, through a RAWG consultation in 1998, as principles fundamental to effective intervention based research. In addition to those addressing the scientific merit of research proposals, the criteria include that research should be sustainable in the community

5.2. OVERARCHING THEMES EMERGING FROM THE CONSULTATION

Information emerging from the current round of RAWG consultations, though covering a wide range of issues, fit within the six themes put forward in the draft RAWG Road Map. While individual themes may benefit from some refinement, on the whole the six Road Map themes form a robust framework to progress an Aboriginal and Torres Strait Islander health research agenda.

Three issues raised repeatedly at the consultation are, however, worth special consideration. These were identified by participants as of over-riding importance and needing to be reflected across all Road Map activity. In some cases, broad research questions were identified and are cited below.

5.2.1 Respect for culture and values

Summary of issues

There was a strong call during the RAWG consultations for the development of a health research agenda focused on Aboriginal and Torres Strait Islander values and culture.

Firstly, the impact of Aboriginal and Torres Strait Islander values and culture on health and resilience was seen as demanding concerted research effort. The presence of a strong cultural and community identity, maintained across the lifespan, was thought to hold the key to individual and community resilience and broader community acceptance.

There are major gaps in understanding about the ways to establish and maintain cultural identity in the face of individual and community diversity and disadvantage. Poor cultural security and the experience of living with racism impacts on Aboriginal and Torres Strait Islander health. It is important to focus on programs that have been successful in combating racism and securing culture.

There was a widely held view that there are issues for the nation to address that in turn impact on health. Strategic policy developments such as native title, slow progress on reconciliation, the portrayal of Aboriginal people and research findings in the media, inadequate community knowledge about Aboriginal and Torres Strait Islander health and the impact of disadvantage, detract from building a compassionate society. There is a need to develop a research program that can contribute to building compassion, trust and respect at a macro-level.

Secondly, respect for Aboriginal and Torres Strait Islander culture and knowledge and a commitment to self-determination should underpin research and the translation of research into policy. The question was asked: “How is ‘Aboriginal knowledge’ accepted and appreciated in policy and the application of applied research?” It was thought that it needed to be made clear to researchers at the outset that local community preferences will drive the research endeavour.

on an ongoing basis, transferable to other communities, and include appropriate community participation in the initiation, implementation and evaluation of research.

Respect for culture must recognise the differences between and across communities and the existence of local value and local meaning. The Aboriginal and Torres Strait Islander population is diverse and this diversity must be explicitly recognised in research design, conduct and implementation. Cultural diversity is itself an area for investigation.

In engaging with research, Aboriginal people are dealing with a system outside their cultural framework and one that has oppressed them. There are lessons from international experience about how to embed self-determination and cultural respect in the research process. Partnerships between researchers and communities will not work if they are not built on respect.

Draft research questions

What are the values of Aboriginal and Torres Strait Islander peoples and how can these be built into policy?

What are the components of cultural identity and security – how can these be established early and reinforced through the life cycle?

What dissonance do Aboriginal and Torres Strait Islander people experience in broader society, in different settings (urban, rural, remote) and from different perspectives (youth, men, women); how does that dissonance relate to health; what solutions may be effective and under what conditions?

Are Aboriginal and Torres Strait Islander people unconsciously socialising their children with poor images of self and identity?

What are the positive models that have addressed the issues of trust and cultural security?

How can public opinion and attitudes be changed to build a more compassionate society and in turn more understanding of Aboriginal culture, Aboriginal health problems and a base for more resources for Aboriginal health?

What are the values (ethical and cultural) that underpin (a) acceptance of Aboriginal community preferences; (b) building of leadership and identity in Aboriginal communities; (c) the building of trust and accountability; (d) cultural security; and how can these best be researched to provide the linkages and the base to create sustainable outcomes?

5.2.2 Achieving health gain

Summary of issues

A fundamental question posed at the four workshops was: “What are the reasons why there have not been health gains for Aboriginal and Torres Strait Islander people?” Research has been conducted and knowledge has become available, but there remains a twenty-year difference in expected lifespan between Aboriginal and non-Aboriginal people and very poor outcomes across the full range of health indicators.

Consistent with the Darwin Criteria, research needs to focus on achieving health gains, be built on collaborative partnerships with communities and across sectors (education, employment, housing), and be funded over a long timeframe to support consultation, building of trust, and translation of findings into action.

Research that will not result in improvements to the lives of Aboriginal people, either because of the research question, the way the research has been developed or the way the research is to be conducted, does not have a place in an Aboriginal health research agenda.

This point may be of such significance as to warrant separate acknowledgment within the RAWG Road Map. One organisation suggested a seventh Road Map theme be added: “An overarching emphasis on intervention research and evaluation of programs working across different sectors, which assesses practical ways to improving health and wellbeing outcomes, particularly drawing on examples of good practice that have been shown to make a difference”.

Draft research questions

Why is change not happening; how does change happen; for whom does change occur and over what timeframe?

What are the success stories in Aboriginal health: why did the interventions work and how can we generalise them?

How do we translate knowledge into effective practice?

What do we currently know from evaluation of policies and programs and interventions about effectiveness/ineffectiveness/unknown effects?

5.2.3 Reforming the research enterprise

Summary of issues

A recurrent theme of the RAWG Workshops was the urgent need to reform the process of conducting Aboriginal and Torres Strait Islander health research to fully reflect the Darwin Criteria.

The research process should have, at its foundation, respect for Aboriginal and Torres Strait Islander communities, empowerment of communities through research and capacity building, and contributing to health gain in community-identified priority areas.

Research must be conducted ethically, with Aboriginal and Torres Strait Islander communities actively engaged in identifying research priorities, defining the research process, participating in capacity building strategies and implementing research findings. This has implications for the research cycle, which should begin with community driven priority setting and progress to implementation and feedback into newly defined community priorities and wider dissemination and translation to other communities.

It was noted that this process requires a significant commitment by research funding agencies and research partners. Time and resources are needed to support community priority setting

and community governance, to build appropriate partnerships between research organisations and communities, to translate findings to practical application, and to maximise learnings and investigate linkages. The research process should link to policy decisions so that sustainable, evidence based programs result.

The responsibility for implementing an ethical Aboriginal and Torres Strait Islander health research agenda along these lines was seen as an important responsibility of the NHMRC but also as going beyond the NHMRC to other research funding agencies, academic and research institutions, and State and Commonwealth governments. Endorsement and implementation of a national Aboriginal and Torres Strait Islander health research agenda and principles should be at the highest level through the Australian Health Ministers Council.

A number of questions were framed at the Workshops under the guise of research questions, but which primarily seek further investigation and reform of the process of doing research and putting findings into action.

These are questions mainly for consideration by government and research bodies as they frame new ways of doing research in the Aboriginal and Torres Strait Islander field. Some of the questions posed were:

- How do we get an ‘across the board’ strategic approach to Aboriginal and Torres Strait Islander health research (including ethics) among the numerous research funding bodies?
- How does a strategic approach to Aboriginal and Torres Strait Islander health research link to national and state health priorities for service development eg funds for implementation of findings?
- How do we ensure that communities are full partners in defining the problem, coming up with solutions, translating, implementing and evaluating?
- What strategies can be used to empower Aboriginal and Torres Strait Islander communities in partnerships with researchers, and improve community research capacity?
- What makes an effective partnership? What strategies might be successful in sustaining partnerships for research over the long haul?

Participants in the RAWG consultations recognised the tensions inherent in developing a national Aboriginal and Torres Strait Islander health research agenda while maintaining a commitment to community driven research.

Aboriginal and Torres Strait Islander populations and cultures are heterogeneous. There is a need to engage at the local level on specific initiatives. In particular, Torres Strait Islander communities sought recognition as a discrete population, with direct and separate consultation on research of importance to them. A further series of questions were posed about the process of deriving community driven research priorities:

- How are local community research priorities established?
- How are local community priorities balanced with other interests such as those of funding bodies, or protocols associated with data collection systems?

- How do we involve the community in determining methods of feedback and interpretation of data (a) for research data generated locally; (b) for research data generated outside the community eg vaccine development, routine surveillance, cancer screening?

5.3 SPECIFIC RESEARCH AREAS AND QUESTIONS

The six themes detailed in the RAWG Road Map were discussed in detail during the consultations. Data was gathered on the range of issues that should be considered within each theme, and the information needed to progress the issues. Broad research questions were framed and prioritised.

While discussions at the workshops in particular were wide-ranging and by no means contained to specific themes, the six Road Map themes do seem to provide a more or less complete framework in which to reflect on consultation outcomes. This section summarises the outcomes of the consultation against each Road Map theme in regard to issues raised, and the research questions identified.

This information is a basis for refinement of the Road Map document, and further development of broad research questions through RAWG. The framing of broad research questions does not imply that consultation with communities, maintaining community choice and conducting research that fully meets ethical requirements are not essential prerequisites for any individual research effort.

5.3.1 Road Map Theme 1

Descriptive research, which outlines patterns of health risk, disease and death. How can this information be utilised to improve the health standards of Aboriginal and Torres Strait Islander people's?

Summary of issues

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;
- 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 health and health care services in Australia;
- providing baseline data for evaluation purposes;
- 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.

5.3.2 Road Map Theme 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.

Summary of issues

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 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 may be more open to health interventions than adolescent boys. 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’ approach was stressed. 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 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?

5.3.3 Road Map Theme 3:

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

Summary of issues

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 people?’ It was noted that one 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 people receive significantly fewer health interventions than non-Aboriginal people 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?’ It was thought that this would lead to 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 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 people? Why do mainstream institutions (hospitals, universities, research agencies) often fail Aboriginal and Torres Strait Islander people?

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 people?

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 modern context?

5.3.4 Road Map Theme 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.

Summary of issues

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 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;
- 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. Some work has also been undertaken in Australia, though this is at an early stage.

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?

What is the impact of technology on health (speed, energy, efficiency, imbalance between affluence and culture)?

How do we map the impact of sectors outside health with health research at the local level?

5.3.5 Road Map Theme 5:

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

Summary of issues

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 often comprised Aboriginal and Torres Strait Islander people 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 settings⁶.
- 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 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.

⁶ 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

- understanding the changing place of men and masculinity in Aboriginal and Torres Strait Islander culture: many communities do not have 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?

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?

5.3.6 Road Map Theme 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 communities.

Summary of issues

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. 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 health workers.

While it was recognised that developing Aboriginal capacity was paramount, it was also seen as crucial:

- to build robust partnerships between Aboriginal and non-Aboriginal partners founded on community priority setting and cultural respect; and
- to develop a high quality non-Aboriginal 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 health workers 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 workforce in high profile management, research, service delivery and policy areas?

What are the characteristics of a successful Aboriginal and Torres Strait Islander researcher?

5.4 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 this report.

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

- could make a difference to Aboriginal health, as defined by Aboriginal 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.

5.4.1 Funding Priorities

A further exercise undertaken at the four workshops was the allocation of a nominal ten million dollars of research funding by each workshop participant to the priority themes identified at each workshop. By aggregating this data, a relative weighting for each theme emerged.

It should not be concluded from this exercise that some themes were unimportant. Rather, the findings reflect the views of participants about the relative distribution of research dollars between themes.

The priority areas for action identified at each workshop were different and the findings of this exercise cannot be aggregated. Nevertheless, at all workshops, a high relative priority was placed on funding research that addressed social determinants of health, cultural identity issues, and what works.

The results from each workshop are provided at Table 2. Further information on the selection and definition of individual priority areas, and the approach and findings of this phase of the consultation are in the individual Workshop reports at Appendices One to Four.

Table 2 : Allocation of nominal research dollars

Priority area	% of budget	Priority area	% of budget
Perth		Darwin	
Identity, racism and culture	20.0	Systems	21.9
Social determinants of health	19.3	What works	20.9
Health over the life course	16.5	Partnerships	20.6
Dealing with the whole person, family community	12.2	Whole of life	20.3
Community empowerment and capacity building	10.6	Regional variation	7.1
Sustainability, funding, agency collaboration	6.7	Disadvantage	6.2
Coping and surviving	6.4	Empowerment	2.9
Equity cost-benefit, values and respect	5.3		
Knowledge/outcomes nexus	3.2		
Brisbane		Melbourne	
Social determinants of health	22.1	Extracting full benefit from knowledge	21.1
Culture and community	21.9	Linkages and capacity	19.0
Research gaps	13.0	Form and financing of health systems	14.9
Continuity and consequences	12.6	Values and quality of health outcome	14.2
Mechanics of research	12.1	Barriers to access	12.2
Existing knowledge	11.0	Research gaps	12.0
Localness'	7.2	Research enterprise	6.7

5.5. CONCLUSION

This section has drawn out the key findings of consultations on the draft RAWG Road Map. Three overarching themes have been identified for further development. Issues and broadly framed research questions for the three overarching themes, and the six specific Road Map themes that emerged from the consultations have been presented. Data has also been presented on the factors that should be considered in assigning relative priority to research questions, and allocating a research budget between competing priorities.

6. RESPONDING TO THE CONSULTATION OUTCOMES

6.1. INTRODUCTION

The consultations on the RAWG Road Map have fully tested its framework and principles, enabling a rigorous investigation of issues and research questions by pooling the knowledge, skills and experience of a cross-section of the Aboriginal, research and government communities.

The consultations have shown the RAWG Road Map to be a robust document, which, with some refinement to incorporate consultation outcomes, can form the centrepiece of an Aboriginal and Torres Strait Islander health research agenda for the next NHMRC triennium.

It is important that RAWG fully considers consultation findings, and develops a response that is transparent to participants and to Aboriginal, government and research communities.

It is recommended that an implementation plan is developed by RAWG in response to the Road Map exercise. A draft plan is described below. The plan may require some refinement when the outcomes of related processes are known, in particular:

- the structures and processes for advancing Aboriginal and Torres Strait Islander in the next triennium of the NHMRC; and
- the review of values and ethics in Aboriginal and Torres Strait Islander health research by the Australian Health Ethics Committee of the NHMRC.

6.2. IMPLEMENTATION PLAN

It is proposed that activities be undertaken predominantly by RAWG, the NHMRC and the Office of Aboriginal and Torres Strait Islander Health to advance five key result areas:

- a refined RAWG Road Map accepted by Workshop participants;
- Road Map outcomes that are widely disseminated and understood;
- implementation of Road Map consultation findings;
- a Road Map that is a living document; and
- the development of linkages.

Table 3 summarises proposed outcomes against each area, the activities recommended to achieve the outcomes, and where the primary responsibility for those activities should lie.

Table 3 : Implementation Areas, Strategies and Primary Role Outcome Area Activities Primary role

Outcome Area	Activities	Primary Role
A. A refined RAWG Road Map accepted by Workshop participants		
1. NHMRC is informed of Road Map consultation and outcomes	Report to the National Health and Medical Research Council on the RAWG consultation process and key findings.	RAWG
2. A refined Road Map reflecting RAWG consultation findings	Review and refine the original RAWG Road Map document to RAWG incorporate key consultation findings as follows: Add three overarching themes addressing culture, health gain and a reformed research enterprise; Incorporate additional issues and broad research questions under each theme. Research questions should be selected and refined by a small working group of RAWG.	RAWG
3. Consultation participants are informed of consultation outcomes and actions	Disseminate a summary of consultation findings and actions to RAWG/NHMRC participants in the RAWG consultations; Post RAWG consultation report(s) on the NHMRC website.	RAWG/ NHMRC
B. Road Map outcomes that are widely disseminated and understood		
4. Key stakeholders understand the Road Map and how it relates to them.	Conduct community workshops to disseminate RAWG outcomes and draw out the implications for different sets of stakeholders eg research bodies, government organisations, Aboriginal community-controlled organisations; Delineate roles and responsibilities for key stakeholders, including Aboriginal and Torres Strait Islander organisations, NHMRC, Commonwealth and State governments, research and academic organisations.	RAWG

Outcome Area	Activities	Primary Role
C. Implementation of Road Map consultation findings		
5. Road Map performance indicators support evaluation and monitoring	Develop performance indicators to enable monitoring of progress on the RAWG Road Map, addressing: <ul style="list-style-type: none"> - the research process - research effort under each Road Map theme - health outcomes - infrastructure and capacity building 	RAWG/ NHMRC
6. Funding of research by the NHMRC supports implementation of Road Map directions	Review structures and processes of the NHMRC for the coming triennium that will support: <ul style="list-style-type: none"> - implementation of the RAWG Road Map - evaluation of progress through monitoring and action on Road Map performance indicators 	NHMRC (with advice from RAWG)
7. Communities, governments and research agencies other than the NHMRC implement the Road Map	Advise the Australian Health Ministers Council, through the Standing Committee of Aboriginal and Torres Strait Islander Health, of the Road Map, and recommend a course of action; <p>Conduct information session for Aboriginal communities, Aboriginal organisations, government agencies and research institutions on the Road Map and its implications.</p>	OATSIH/ NHMRC/ RAWG
8. Information to support further development of the Road Map and targeted research is available	Coordinate a review of research gaps through strategic consultation and an audit of current data and research; <p>Conduct information session for Aboriginal communities, Aboriginal organisations, government agencies and research institutions on the Road Map and its implications.</p>	OATSIH/ NHMRC/ RAWG
D. A Road Map that is a living document		
9. The Road Map is refined regularly to reflect changing priorities, identified in consultation with the community	Annual feedback and priority setting workshops are conducted with representatives of the Aboriginal and Torres Strait Islander, research and government sectors; <p>The Road Map is revised to reflect the outcomes of the annual consultation and the knowledge emerging from review of data and research and progress against performance indicators.</p>	RAWG/ NHMRC

Outcome Area	Activities	Primary Role
D. Development of linkages		
10. There is a coherent, collaborative approach in Road Map related areas	<p>The government and NHMRC response to the Road Map and action arising reflects related developments such as the review of NHMRC structures and processes and the findings of the review of ethics guidelines;</p> <p>Information sessions, conducted under Item 7, also educate relevant sectors on the NHMRC and the process of conducting ethical research.</p>	RAWG/ NHMRC
11. Data linkage is promoted	Facilitate a review of Aboriginal and Torres Strait Islander health information systems, including quality and accessibility of data, and data ownership, and identify opportunities and strategies to link data.	OATSIH/ NHMRC

7. CONCLUSION

This completes the report to RAWG on the findings of the consultation workshops and written submissions on the RAWG Road Map.

The consultation process on the RAWG Road Map has been highly successful both in terms of the number and diversity of individuals and organisations involved, and the quality of data collected.

Detailed reports on the workshops and submissions are at Appendices One to Five. These individual reports hold an abundance of material on research priorities, the interrelatedness of individual themes and the context in which research is occurring. Members of RAWG are encouraged to consider the reports in their entirety.

The next step for RAWG is to close the loop for participants by reporting back on consultation outcomes and advising on next steps. It is crucial that this occurs to reflect a shared commitment to community participation and feedback and to develop a sound basis for ongoing collaboration as the RAWG Road Map progresses as a living document.

ATTACHMENT ONE: MEMBERS OF THE ABORIGINAL & TORRES STRAIT ISLANDER RESEARCH AGENDA WORKING GROUP

Name	Position
Delaney, John - Mr	CHAIR
Arabena, Kerry - Ms	Executive Director ACT Family Planning Association and Representative, Health Advisory Committee
Bowie, Phillip - Mr	Torres Strait Regional Authority; and Project Officer with Cairns District Health Service
Boyer, Kim - Ms	Chief Executive Officer Tasmanian Division of General Practice; and Representative, Strategic Research Development Committee
Clarkson, David - Mr	Director Research Development Section, Office for NHMRC
Dunbar, Terry - Ms	Co-operative Research Centre for Aboriginal and Tropical Health
Eades, Sandra - Dr	Telethon Institute for Child Health Research
Elston, Jacinta - A/Prof	Head Aboriginal and Torres Strait Islander Studies Unit, School of Public Health and Tropical Medicine, James Cook University
Evans, Helen - Ms	First Assistant Secretary Office for Aboriginal and Torres Strait Islander Health
Nangala, Stanley - Mr	Chair Standing Committee for Aboriginal and Torres Strait Islander Health (SCATSIH), QLD Health
O'Dea, Kerin - Prof	Office for NHMRC – Council
Ritchie, Craig - Mr	Chief Executive Officer National Aboriginal Community Controlled Health Organisation
Thomas, Preston - Mr	Commissioner Aboriginal and Torres Strait Islander Health Commission WA
Weetra, Colin - Mr	South Australian Centre for Rural and Remote Health, University of SA