Cancer Council NSW
Online submission to the Aboriginal Health Plan for NSW

January 2012
Aboriginal Health Plan for NSW

INTRODUCTION

We welcome you to respond to the questions that follow and appreciate the time you take to do so.

Information to help you complete the survey:

• There are ten key themes which we anticipate will be addressed under the NSW Aboriginal Health Plan.

• For each key theme there are a set of 4 questions. Having the same response section for each will allow responses to be compiled and analysed and a comprehensive report to be prepared.

• Preceding the questions for each theme there are prompt questions that may generate thoughts and inform your response.

• Below the questions there is commentary and evidence which may also inform your response.

• Although the questions may be broad, please be as practical and specific as possible with examples where possible.

• You can respond then respond under any or all of the questions.

• If you prefer to provide a more general response you may go to the very last question. It would be preferable to consider the thematic questions first to provide context for your response.

• Submissions must be received by Friday 13 January 2011.

• Your name and contact details are required. These details will not be used for any purpose other than this consultation process and documents will be retained only as prescribed by government guidelines.

• To print you will need to print each page separately as you go.

• The survey could take less than an hour. However it’s really up to you how much you would like to say and how much time you have to say it!

• Submissions must be received by Friday 13 January 2011.

Thank you

Note:
Please note that where a question asks about the NSW Health system it is specific to the public health system, which is the responsibility of the NSW Government. Where a question refers to the health system it is referring to all parts of the health system in NSW.
Section 1. Ensuring the health of Aboriginal people is everyone’s business

Consider:

- What health system changes are required to enable everyone in the health system to contribute to improving Aboriginal health, from the Ministry of Health to front line workers?
- What strategies can be put in place to ensure that all NSW Health services respond to the needs of Aboriginal people?
- How can Aboriginal Health Impact Statement be better utilised to support the NSW Health system?

Closing the gap in health outcomes between Aboriginal and non-Aboriginal people requires a significant shift in the way Aboriginal health is considered across the health system – towards making Aboriginal health everyone’s business and away from a silo approach where responsibility for Aboriginal health falls to one particular health stream.

The Australian Government’s Strategic Review of Indigenous Expenditure noted that “the creation of separate programmatic and bureaucratic structures for Indigenous affairs carried the obvious risk – all too often realised – that other areas… would view Indigenous matters as falling outside their own sphere of concern, and would thereby disregard or downplay their responsibilities to Indigenous Australians”.

Achieving the closing the gap targets will depend critically on a shared vision for Aboriginal health across the health system, and on improvements in the quality and uptake of the mainstream services delivered to Aboriginal people.

10. What does this look like when we have achieved success?

Cancer Council NSW is the leading cancer charity in NSW, for all cancers and all people. Cancer is the second biggest killer of Aboriginal people in NSW, accounting for 21.1% of deaths among Aboriginal people in 2003-2007.[1]

Aboriginal people have substantially higher cancer mortality rates than the general population. Standardised mortality rates for all cancers combined are 66% higher for Aboriginal males and 59% higher for Aboriginal females compared to the NSW population.[2] For some types of cancer, the disparity is even greater. Among Aboriginal females, the mortality rate for kidney cancer is 3.8 times the rate of NSW females generally; for cervical cancer 3.7 times; and for lung cancer twice the rate of NSW females. Among Aboriginal males, the biggest discrepancies are in oesophageal cancer (3 times the mortality rate of NSW males generally), stomach cancer (2.5 times), pancreatic cancer (1.8 times), and indefinite and unspecified cancer sites (1.8 times).

Aboriginal people with cancer tend to be diagnosed later than non-Aboriginal people, may not access or complete cancer treatment, and have many unmet needs for practical, financial and emotional support. Cancer risk factors such as smoking, obesity, hepatitis B carrier status, low fruit and vegetable consumption and low rates of participation in screening programs are more prevalent in Aboriginal populations.

Cancer Council NSW is leading the Aboriginal Patterns of Cancer Care (APOCC) study, the largest study to date of cancer care for Australian Aboriginal people. Our programs in tobacco control, nutrition, cancer awareness, and cancer support and information services are also relevant to Aboriginal communities (see question 12). We acknowledge that we have a way to go in making our programs relevant and effective for Aboriginal people, and we are actively working towards this goal.

When we have achieved success in ensuring the health of Aboriginal people is everyone’s business, the health system will effectively meet the unique needs of Aboriginal people in programs for cancer prevention, screening,
treatment, end of life care and support, and cancer will be recognised as a core issue in Aboriginal health alongside other chronic conditions. In the long term:

- the prevalence of cancer risk factors among Aboriginal people will be reduced to that of the general population
- there will be no gap in cancer survival or mortality between Aboriginal people and non-Aboriginal people
- Aboriginal people will have easy access to culturally safe cancer screening, diagnostic, treatment, and end of life services, and will feel welcome and comfortable in mainstream health services
- Aboriginal people with cancer and their families will have easy access to culturally safe practical, financial and emotional support services, including transport to treatment and accommodation
- Aboriginal people and communities will have a hopeful approach to a cancer diagnosis
- Aboriginal people and communities will be socially and economically empowered to practice healthy behaviours, in line with a social determinants approach to health
- a cross-sectoral approach will ensure that education, economic, social and housing policies work together to improve health outcomes in Aboriginal communities.


11. What is working well - include examples of good practice?

Cancer Council NSW is involved in the following programs, which provide examples of good practice in making Aboriginal health part of the business of a mainstream organisation.

Cancer Council NSW has a memorandum of understanding with the Aboriginal Health & Medical Research Council and is also developing a Reconciliation Action Plan.

Aboriginal Patterns of Cancer Care (APOCC) study

APOCC is a research collaboration between Cancer Council NSW, the University of NSW and the University of Sydney and funded by the National Health & Medical Research Council. It is the largest study to date of cancer care for Australian Aboriginal people.

The first phase of the APOCC study comprised 58 qualitative interviews with Aboriginal cancer survivors, carers and health care workers about their experience of cancer care. This phase is nearing completion. The second phase has collected treatment data for 1324 Aboriginal people diagnosed with cancer, identified through NSW hospitals and Clinical Cancer Registries. Data from this phase are now being analysed. The third phase of the APOCC study is investigating the experiences of Aboriginal people leading up to diagnosis of their cancer. It aims to identify factors that delay or impede diagnosis. Interviews for this phase are now underway.

Results from the APOCC study will improve understanding of the factors contributing to high cancer mortality rates for the NSW Aboriginal population and inform future policies and practices to improve survival.

Cancer co-morbidity, treatment, survival and end of life care for Aboriginal people in NSW (APOCCLink)

This is a collaborative study with the University of Sydney and Sacred Heart Hospice, funded by Cancer Institute NSW. It will link datasets from the second phase of the APOCC study with the NSW Central Cancer Registry, hospital and emergency department episodes and deaths data.
Analysis of this linked dataset will allow us to, for the first time, describe the relationships between cancer treatment, co-morbidities, survival and end of life care for Aboriginal people. It is intended that APOCCLink will make a significant contribution to policies and planning of optimal cancer treatment and end of life services for Aboriginal people in NSW.

‘Aboriginal cancer journeys’ booklet and factsheets


Tackling Tobacco program

Cancer Council NSW’s ‘Tackling Tobacco’ program aims to reduce smoking related harm among disadvantaged groups, including Aboriginal people. It includes a small grants program that has been successful in building community service organisation capacity and partnerships. The grants were publicised via networks where they would reach Aboriginal services, and three out of 20 projects have Aboriginal clients:

- Albury Wodonga Aboriginal Health Service
- The Men’s Shed at Emerton (part of Jesuit Social Services – the area has a high Aboriginal population and the project funded was for Aboriginal clients)
- a Barnados project to create an Aboriginal worker support network to quit smoking.

Learnings from these projects show that the following factors are important to success with hard-to-reach groups:

- innovative approaches to integrating health programs with existing services and settings, such as delivering quit counselling and free nicotine replacement therapy through community service organisations that are already engaged with target communities
- acknowledging that many of the solutions for improving health outcomes lie outside the health sector
- workforce capacity building.

Eat It To Beat It nutrition program

‘Eat it To Beat It’ is a nutrition program to encourage families with primary school aged children to eat more fruit and vegetables, to improve health and wellbeing and help prevent chronic disease. Inadequate fruit and vegetable consumption is estimated to be responsible for 2.1% of the total burden of disease in Australia, ranking seventh of 14 risk factors studied by the Australian Institute of Health and Welfare. [3]

Data from the most recent National Aboriginal and Torres Strait Islander Health Survey identified that 56% of Indigenous Australians had a low daily consumption of both fruit and vegetables (i.e. one or less serves of fruit and four or less serves of vegetables[4]), and Indigenous Australians were more than nine times more likely than non-Indigenous Australians to not usually consume either fruit or vegetables on a daily basis. [5] The ‘Eat It To Beat It’ program has been operating successfully in the Hunter region for four years. After extensive evaluation, the program is now ready to be rolled out across NSW, with a focus on Aboriginal Australians and rural and remote communities. In 2011, the Cancer Council NSW undertook extensive community consultations to determine the feasibility of developing an ’Eat It To Beat It’ Aboriginal strategy. Selected key stakeholders were asked to discuss barriers to fruit and vegetable consumption for their Aboriginal community. Overwhelmingly, the main barrier cited was the price of fruit and vegetables. (More barriers are listed under question 12).

In 2012, Cancer Council NSW hopes to build on the success of the ‘Eat It To Beat It’ program and partner with Aboriginal organisations to develop a culturally appropriate fruit and vegetable program for Aboriginal communities.

NSW Aboriginal Cancer Program

Cancer Council NSW has partnered with the AH&MRC and Cancer Institute NSW to develop the NSW Aboriginal Cancer Program, funded by NSW Health, which has the overall goal of improving cancer care for Aboriginal people in NSW. Cancer Council NSW is involved in the following elements:

Cancer Council NSW | Online submission to the Aboriginal Health Plan for NSW | January 2012
workshops with Aboriginal communities to raise cancer awareness and identify solutions
workshops for community action (advocacy) and establishment of an Aboriginal cancer community action network.

The cancer awareness workshops will build on a model used by AH&MRC and Cancer Council NSW to deliver similar cancer awareness workshops in earlier years. The workshops will include information sessions targeting Aboriginal community members, facilitated discussions about local issues of importance to the Aboriginal community, distribution of available resources and identification of resources needed, and the development of a plan to guide future local action for cancer screening, treatment and support services. An Aboriginal facilitator will be involved in the delivery of all workshops, and arrangements will be made for easy access to culturally appropriate counselling and other support for participants should it be needed. The opportunity for Aboriginal communities to be supported to host a workshop will be promoted through various AH&MRC, Aboriginal Community Controlled Health Services and other Aboriginal community networks.

The community action (advocacy) workshop follows the success of a similar workshop for Aboriginal people delivered by the AH&MRC and Cancer Council NSW in 2009. This workshop will be offered once a year in different regional locations, with funds for participants’ transport and accommodation. Follow-up will assist participants to develop local projects. An Aboriginal cancer community action network will be established, with participants in previous and proposed workshops being invited to join, as well as other Aboriginal community members interested in working together on cancer. This network will be supported by the AH&MRC and Cancer Council NSW, and will enable information sharing about issues and strategies specific to the experiences of Aboriginal people.


12. What is not working well - identify barriers?

Early findings from the APOCC study suggest that for some cancers at least, Aboriginal people are receiving similar levels of surgical treatment to non-Aboriginal people. However, the acceptability and accessibility of chemotherapy and radiotherapy are less clear.

The qualitative interviews from the APOCC study and research in Western Australia[6] have identified the following barriers to cancer diagnosis and treatment for Aboriginal people in mainstream health services:

- lack of trust in health and support services
- unfamiliarity with cancer, and poor communication from health services about what is involved in cancer treatment and what to expect
- feelings of shame, stigma and fatalism associated with a cancer diagnosis
- lack of appropriate transport, accommodation and childcare services, including accommodation for families travelling with the patient
- costs of medical imaging, treatment, medicines, travel and accommodation, especially where people are losing income during treatment
- complexity and inadequacy of reimbursement arrangements (such as IPTAAS)
- lack of information about available support services and costs (Aboriginal people may not approach support services even if they are aware of them, because they are wary about incurring costs)
- inflexible appointment times
- isolation, being away from family, and feelings of fear and alienation in a hospital environment (which may also deter family members from visiting the patient, adding to isolation)
- inability and/or inflexibility in hospitals in providing space for a number of visitors
- insufficient Aboriginal Liaison Officers or other Aboriginal staff.
Consultations with Aboriginal communities in relation to the ‘Eat It To Beat It’ nutrition program identified the following barriers to fruit and vegetable consumption:

- high prices for fruit and vegetables in relation to low incomes
- lack of facilities for food storage, preparation and cooking
- housing conditions (houses are overcrowded, and food must be shared with others living in the house, meaning any fresh food and purchased does not last for the week)
- lack of personal or public transport to shops that sell fruit and vegetables
- feeling uncomfortable in local shops
- easy access to take-away food.

More broadly, the underlying barriers to cancer prevention and treatment relate to the social determinants of health, such as income inequality, education, housing, crime, social exclusion, and mistrust of health and social services because of historical or current experiences of racism.


13. What specific recommendations would you make – identify opportunities

Programs to address the barriers to cancer prevention, screening, diagnosis, treatment, support and end of life care for Aboriginal people should be developed in collaboration with Aboriginal people, organisations and communities, allowing mainstream and Aboriginal organisations to share skills and experience. Specific recommendations include:

- provide cultural competency training for staff in cancer services
- improve awareness of cancer prevention and cancer care among Aboriginal health workers and community members
- provide opportunities for Aboriginal people to tell stories of cancer survival
- improve awareness of cancer as an Aboriginal health issue among mainstream primary care providers
- improve access to and affordability of cancer screening, primary health care and diagnostic services
- develop procedures for routine assessment of Aboriginal patients’ and carers’ needs for practical, psychosocial and financial support, and assistance with appropriate referrals
- routinely provide explicit financial information about all referrals, treatment options and support services
- provide free services or immediate financial assistance rather than reimbursement
- provide culturally safe accommodation and transport services for Aboriginal cancer patients and families
- make cancer services more welcoming for Aboriginal people, for example by employing Aboriginal staff, providing outdoor spaces and using local Aboriginal artwork
- provide culturally safe care coordination services for Aboriginal patients that involve family members, primary care providers and other services as appropriate
- facilitate partnerships between government, the health sector, food businesses and community organisations to improve access to fruit and vegetables and other healthy food choices
- provide opportunities for Aboriginal individuals and organisations to develop and deliver health promotion programs to Aboriginal communities.

Recommendations to begin to address the social determinants of health include:

- major programs to support early childhood development, family functioning and educational attainment
- improve living and working conditions for Aboriginal communities
- attention to equity as an important objective in social and economic policy.
Section 2. Achieving cultural security and a whole of life view of health

Consider:

- How can the NSW Health system ensure that health services are accessible and delivered in a culturally secure way, recognising a whole of life view of health?
- What is best practice in achieving cultural security in health system settings? What are barriers to achieving cultural security in all health services, and strategies to address them?

“‘Aboriginal health’ means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-being of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life. Health care services should strive to achieve the state where every individual is able to achieve their full potential as a human being and this bring about the total well-being of their community.” (National Aboriginal Health Strategy, 1989)

One definition of cultural security is “the maintenance and protection of cultural identity. It is a policy and practice by which health providers and individuals recognise the diversity of Aboriginal and Torres Strait Islander culture in delivery of appropriate health services. Mainstream health providers are required to work in partnership with Aboriginal and Torres Strait Islander organisations to develop culturally secure health services. Areas of medicine such as birthing, palliative care and care of elders need to offer culturally appropriate options for Aboriginal and Torres Strait Islander people. Cultural security is the next step in strengthening community leadership, for attitudinal and behavioural change in mainstream society and within the Aboriginal and Torres Strait Islander community. It will also set the benchmark for best practice models in service delivery for Aboriginal and Torres Strait Islander people.” (WA Health, 2000)

A Best Practice Approach to Cultural Competence Training notes that: “Cultural Security is built from the acknowledgement that theoretical
‘awareness’ of culturally appropriate service provision is not enough. It shifts the emphasis from attitudes to behaviour, focusing directly on practice, skills and efficacy.”

14. What does this look like when we have achieved success?

When we have achieved success in achieving cultural security and a whole of life view of Aboriginal health, indicators will be:

- access to health services and levels of patient and carer satisfaction among Aboriginal people will be similar to or better than among non-Aboriginal people
- local Aboriginal communities will be consulted before, during and after the development of new cancer programs and services, with attention to the time needed for genuine consultation, the appropriate protocol required, and the practical needs of participants (such as transport)
- culturally appropriate facilities and infrastructure would be routinely included in the planning of all new and redeveloped cancer and palliative care services, e.g. outdoor spaces, space for large families to visit and accompany patients, and suitable transport and accommodation.
15. What is working well - include examples of good practice?

16. What is not working well - identify barriers?

17. What specific recommendations would you make – identify opportunities?
Section 3. Embedding equity throughout the health system

Consider:

- How can health system policies, practices and processes change to remove inequities in health outcomes between Aboriginal and non-Aboriginal people? Please be specific in relation to the policy/process/practice you are referring.
- Has interpersonal racism in the health system successfully been addressed?
- If so, what are mechanisms and strategies that can be more widely adopted?
- How can the NSW Health system better engage Aboriginal people and communities in health system structures and processes to support equity in health outcomes?

In addition to ensuring culturally appropriate service delivery, system change is required to ensure that structures, processes and relationships across the health system lead to equity in outcomes for Aboriginal people. The disadvantage experienced by Aboriginal Australians is associated with both historical and contemporary racism, colonisation and oppression (Paradies, et al: 2008), and there is growing research around the prevalence of racism experienced by Aboriginal people in Australia generally.

The Overcoming Indigenous Disadvantage report indicates that 38.3% of Indigenous people reported being treated badly because they were Aboriginal/Torres Strait Islander, and this was a key stressor leading to high/very high levels of distress, and 61.0% reported that it lead to low/moderate levels of distress in the last 12 months (Table 7A.7.6).

The impact of racism across the health system is also becoming more widely acknowledged and understood, with increasing literature considering racism in health care (see for example The Impact of Racism on Indigenous Health in Australia and Aotearoa: Towards a Research Agenda), and significant anecdotal evidence suggesting that institutional racism (where requirements, conditions, policies, practices, processes maintain or reproduce avoidable and unfair inequities across ethnic/racial groups); interpersonal racism (interactions between people that maintain or reproduce avoidable and unfair inequities – eg racial abuse) and internalised racism (acceptance of attitudes, beliefs or ideologies by a member of an ethnic/racial group about the inferiority of one’s own ethnic/racial group) (Paradies, et al: 2008); exists in the NSW health system, alongside culturally inappropriate service delivery.
18. What does this look like when we have achieved success?

19. What is working well - include examples of good practice?

20. What is not working well - identify barriers?

21. What specific recommendations would you make – identify opportunities?
Section 4. Addressing gaps in the patient journey and supporting care coordination

Consider:

• Please provide examples of effective patient journeys for Aboriginal people through the care continuum of the NSW health system?

• How can a culturally appropriate and effective patient journey be achieved?

• Where are the gaps in the patient journey? How can coordination between primary health care, community health, out-patient, in-patient and specialist services be enhanced?

The NSW Government has committed under the National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes to fix the gaps and improve the patient journey as a priority area of action. NSW has been developing work in this area, and much of it aims to ensure that Aboriginal people in NSW receive treatment when they need it, are able to access services, and make positive health care choices.

The NSW State Plan further commits to reducing potentially preventable hospitalisations by refocussing efforts on keeping people healthy and out of hospital through improving the way conditions are managed in a primary or community setting.

Furthermore, Aboriginal people’s experience of the health system can be different than for non-Aboriginal people and there is a need to better understand what the journey looks and feels like from an Aboriginal perspective.

22. What does this look like when we have achieved success?

23. What is working well - include examples of good practice?

24. What is not working well - identify barriers?

Gaps in the patient journey and barriers to care coordination for Aboriginal people with cancer include:

- low participation rates in cancer screening programs
- late diagnosis
- failure to continue or complete treatment
- insufficient numbers of Aboriginal liaison officers or other Aboriginal staff in hospitals and cancer services
- lack of cultural security for Aboriginal people in mainstream health services
- reluctance among cancer health professionals to acknowledge that Aboriginal patients and families may have particular support needs (instead, they may try to ‘treat everyone the same’).

(See also response to question 12).
25. What specific recommendations would you make – identify opportunities?

- Develop strategies to improve communication and continuity of care between cancer services and Aboriginal Community Controlled Health Services (especially upon referral to, and discharge from, the cancer service, e.g. integrated psychosocial care planning and discharge planning with the involvement of Aboriginal health workers and Aboriginal Community Controlled Health Services).
- Consider employing designated Aboriginal cancer care coordinators or Aboriginal health workers in oncology (for example, Aboriginal health workers or outreach workers working alongside cancer care coordinators in each Local Health District).
- Continue to develop targeted information and education about Aboriginal cancer care for health professionals and service managers.

(See also response to question 13.)
Section 5. Creating a strong and supported Aboriginal workforce

Consider:

• What mechanisms and strategies could be adopted to support recruitment and retention targets in the health system?
• What more needs to be done to promote and support Aboriginal people into leadership roles across the health system?
• How can more Aboriginal people be attracted to careers in the health system?
• What are examples of effective education and training initiatives supporting Aboriginal people in the workforce? How can these be enhanced or expanded?

Aboriginal people have a vital contribution to make to the health system workforce that needs to be recognised and respected.

NSW Health is committed to developing the Aboriginal health workforce, including employing at least 2.6% Aboriginal people, and the Ministry of Health has recently released an Aboriginal Workforce Strategic Framework to meet this commitment. The Ministry of Health has also released Respecting the Difference: An Aboriginal Cultural Training Framework for NSW Health.

26. What does this look like when we have achieved success

27. What is working well - include examples of good practice

28. What is not working well - identify barriers.

Aboriginal liaison officers in hospitals have a high caseload and lack support.

29. What specific recommendations would you make – identify opportunities

• Increase numbers/capacity of Aboriginal liaison officers to support cancer patients, including outpatients.
• Continue to improve education, with recognised qualifications and a defined career path, for Aboriginal health professionals in oncology.
• Provide professional education and networking opportunities relating to Aboriginal cancer care for Aboriginal health workers, cancer care coordinators and other health professionals.
• A policy framework for increasing the numbers of Aboriginal staff in non-government organisations, and providing support for these staff.
Section 6. Embedding genuine accountability and transparency

Consider:

- How can responsibility for delivering against funding for Aboriginal health be better embedded throughout the health system to ensure accountability and transparency?
- How can accountability and transparency for the allocation and expenditure of Aboriginal health funds be achieved across the health system?
- What is the best way to involve the community and peak bodies in determining accountability for funding allocation and delivery against this funding?

NSW Health is accountable for public expenditure through long-term funding and meaningful planning and service development in genuine partnership with communities. There is accountability for services provided and for effective use of funds by both the mainstream and Aboriginal community controlled health services. The NSW Government is ultimately responsible for ensuring that all people in NSW have access to appropriate and effective health care. The NSW Auditor General’s Report on Two Ways Together – NSW Aboriginal Affairs Plan recommended that there is compliance by NSW Government agency heads with the reporting requirements on Aboriginal targets as part of their performance agreement and that agencies develop a plan to regularly review compliance and results.

The need for stronger accountability is echoed in the Ombudsman’s report which notes that “the currently fragmented approach to the planning, funding and delivery of services to Aboriginal communities, and the absence of adequate mechanisms for holding agencies to account against their responsibilities, must also be addressed”.

30. What does this look like when we have achieved success?

31. What is working well - include examples of good practice?

32. What is not working well - identify barriers?

33. What specific recommendations would you make – identify opportunities?
Section 7. Supporting innovative approaches and building the evidence

Consider:

- How can the NSW Health system work effectively in partnership with Aboriginal communities to both create and use relevant and useful evidence when developing and implementing programs?

- How can the NSW Health system better support and promote innovative approaches to Aboriginal health from locally identified best practice?

The challenges of Aboriginal health are great – and there is a need to get smarter about the way we work, direct our funding and purchase services in order to ensure that the closing the gap targets are met. The Strategic Review of Indigenous Expenditure noted that “past approaches to remedying Indigenous disadvantage have clearly failed, and new approaches are needed for the future.”

More new and innovative, sustainable and scalable approaches need to be developed to address gaps in the health system, and at the same time build the evidence and create program and service delivery models that work and can be adopted and implemented widely. There is very limited evidence about effective health approaches and interventions in the Aboriginal health setting.

The NSW Ombudsman’s recent report Addressing Aboriginal disadvantage: the need to do things differently noted that “recent reviews of major Aboriginal initiatives in NSW have demonstrated the poor return on [the] level of investment”. The Ombudsman’s report also notes that the Strategic Review of Indigenous Expenditure found that in relation to addressing Aboriginal disadvantage, substantial government investments have “yielded dismally poor returns to date” and the Ombudsman’s report notes that “greater investment is needed to address the underlying causes of Aboriginal disadvantage, rather than simply treating the symptoms”.

The Ombudsman’s report also notes that too often programs are inadequately designed, poorly targeted and their effectiveness not evaluated. The inconsistent commitment to program evaluation means that there is often not a clear picture of which pilot programs have resulted in improvements.

The Auditor General’s report on Two Ways Together also noted that more rigorous evaluations would enable a better evidence base of what contributes to program success, and without this it is difficult to say whether funding is going to where it can be most effective, funding is properly allocated, funding is spent on the program it is allocated to and government services are being used.

34. What does this look like when we have achieved success?

- There will be a strong evidence base to underpin effective programs to improve Aboriginal cancer outcomes that also allows programs to be tailored according to local needs and priorities.
35. What is working well - include examples of good practice?

36. What is not working well - identify barriers?

37. What specific recommendations would you make – identify opportunities?

Cancer Council NSW recommends the following, which partly draw upon the NHMRC Road Map for improving Aboriginal and Torres Strait Islander health through research:[7]

- ongoing descriptive research that outlines patterns of health risk, disease and death: for example, ongoing monitoring of cancer outcomes for Aboriginal people and evaluation against the NSW Cancer Plan
- a research focus on the factors and process that promote resilience and wellbeing, in particular, but not exclusively, during pregnancy, infancy, childhood and adolescence, and form the basis for good health throughout the lifespan
- a focus on health services research relating to delivering health services and programs to Aboriginal people: for example, translational research arising from the results of the Aboriginal Patterns of Cancer Care study, to develop and implement strategies to improve cancer prevention, screening, treatment, end of life care and support for Aboriginal people with cancer
- a focus on the association between health status and policy and programs outside the health sector: for example, exploring the economic, social, education and housing factors that support fruit and vegetable consumption and physical activity in families with children
- a focus on engaging with research and action in previously under-researched Aboriginal populations and communities: for example, urban communities
- development of Aboriginal health research capacity, including training Aboriginal researchers
- flexibility in timelines for evaluation and research, to allow time to build relationships between Aboriginal and mainstream communities and organisations, to obtain ethics approval, and to ensure meaningful Aboriginal community engagement/leadership
- explore innovative approaches to involving community members in developing program resources (which may include social media, storytelling approaches or hands-on activities), as an alternative to traditional print and media resources.

Section 8. Building the capacity of health services and communities

Consider:

- How can the role and capacity of the Aboriginal community controlled health sector be effectively enhanced? What are the barriers to building capacity, and how might they be addressed?

- How can mainstream NSW Health services play a more active and effective role driving and supporting the growth in capacity of the Aboriginal community controlled sector? What are examples of successful capacity building?

Strengthening health services and building community expertise to respond to health needs will be crucial to long term change. As the Ombudsman's report Addressing Aboriginal disadvantage: the need to do things differently notes, “our ultimate goal should be to empower Indigenous people and communities... so that they can progressively take meaningful control of their futures,” and notes that: “it is critical that government works in partnership with Aboriginal leaders to build the ‘social and economic’ capital within Aboriginal communities”.

38. What does this look like when we have achieved success?

39. What is working well - include examples of good practice?

40. What is not working well - identify barriers?

41. What specific recommendations would you make – identify opportunities?
Section 9. Valuing self determination

Consider:

- How can principles of self-determination be better understood, respected and observed in the NSW Health system?

- What are strategies that mainstream health services can put in place to improve collaboration and partnerships with Aboriginal community controlled health services?

The practical exercise of self-determination is central to Aboriginal health, and the underpinning principle of the Aboriginal Health Partnership Agreement. Self determination can also be understood within the wider context of the Rights of Indigenous People’s. Several statements reaffirm Indigenous rights, the most recent being the UN Declaration of the Rights of Indigenous Peoples, which notes: “Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programs affecting them and, as far as possible, to administer such programmes through their own institutions.” (Article 23)

There is ambiguity around what self-determination means and how it can practically be realised, and principles of self determination for Aboriginal people are not always well understood or respected across the health system.

42. What does this look like when we have achieved success?

The AH&MRC Strategic Plan 2011-2014 lists the following signposts of positive impact in the area of self-determination:[8]

Aboriginal health funding, planning, implementation and evaluation decisions in NSW:
- are based on the knowledge and expertise of the Aboriginal Community Controlled Health sector;
- reflect locally-based health needs and priorities
- result in increased resource allocations over longer timeframes that match the level of need.


43. What is working well - include examples of good practice?

44. What is not working well - identify barriers?

45. What specific recommendations would you make – identify opportunities?
Section 10. Recognising grief, loss and trauma

Consider:

- What system changes or initiatives need to be made to recognise and respond to trans-generational trauma and loss throughout the NSW Health system?

- How can the government build greater trust with Aboriginal people and communities?

- What can the health system do to support Aboriginal people and communities to achieve social and emotional wellbeing?

The increased burden of disease carried by the Aboriginal population cannot be fully explained by socioeconomic disadvantage alone or in combination with other health risk factors, such as smoking, risk drinking, and poor housing (AIHW, 2008). The impact of colonisation on the loss of land has undermined the economic, spiritual and cultural basis of Aboriginal society and may contribute to poorer health (AIHW, 2008).

Many of the problems prevalent in Aboriginal communities today—alcohol abuse, mental illness and family violence (which themselves perpetuate the cycle of trauma) – have their roots in the failure of Australian governments and societies to acknowledge and address the legacy of unresolved trauma still inherent in Aboriginal and Torres Strait Islander communities. (Professor Judy Atkinson in Voices from the Campfire Report)

Addressing issues of loss and trauma will be critical to the success of services and programs, and greater recognition is needed to consider the impact of trans-generational trauma and loss, to ensure trauma informed care and practice, and to recognise past-government practices as contributing to the gap in Aboriginal health and equality. The Ministry of Health has recognised this for example through the signing of the Statement of Commitment, and some former Area Health Services have made similar acknowledgements and commitments.

The NSW Ombudsman’s report also notes the need to “provide substantial support to healing programs that have been endorsed by Aboriginal communities”.

46. What does this look like when we have achieved success?

47. What is working well - include examples of good practice?

48. What is not working well - identify barriers?

49. What specific recommendations would you make – identify opportunities?
Other information

Please make any additional comments below:

50. Are there any other comments you would like to make?

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