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**Cancer Service Networks
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cancer services for better
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Australian Government

Cancer Australia



Aboriginal and Torres Strait Islander Cancer Control Research Project

Authors: Miller, J., Knott, V., Wilson, C.,
Cunningham, J., Condon, J., Roder D., et al. (July
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Investigator Team (in alphabetical order)

Ms Jacqueline Bowden (Manager, Behavioural Research and Evaluation Unit, CCSA; Manager, Tobacco Control Research and Evaluation Program, CCSA).

Mr Alwin Chong (Senior Research and Ethics Officer, Aboriginal Health Council, South Australia).

Associate Professor John Condon (Principal Research Fellow, Menzies School of Health Research; Senior Specialist Public Health Medicine (Epidemiologist), Health Gains Planning Branch, NT Department of Health and Families; District Medical Officer, Remote Health Services, NT Department of Health and Families).

Professor Joan Cunningham (Senior Principal Research Fellow (Professor) & NHMRC Research Fellow, Menzies School of Health Research; Professor/Adjunct Professor, Menzies School of Health Research, Charles Darwin University; Honorary/Adjunct Associate Professor, University of Melbourne; University of Sydney; Flinders University of SA).

Ms Tracey Doherty (Clinical Practice Nursing Director, CNAHS Cancer Services; Oncology Nurse Practitioner, Royal Adelaide Hospital Cancer Centre; Deputy Chairman, Statewide Cancer Clinical Network Steering Committee, SA Health).

Ms Kalinda Griffiths (Indigenous Project Officer, Menzies School of Health Research).

Dr Vikki Knott (Senior Project Officer, CCSA; Visiting Research Fellow, School of Psychology, University of Adelaide, Senior Lecturer, Discipline of Psychiatry, School of Medicine, University of Adelaide).

Ms Carmel McNamara (Coordinator, Aboriginal Cancer Control Program, CCSA; Co-Chair, Aboriginal and Torres Strait Islander Committee, Cancer Council Australia).

Ms Caroline Miller (General Manager, Cancer Control Programs, CCSA; Associate Lecturer, Discipline of Public Health, University of Adelaide).

Professor David Roder (Research General Manager, Cancer Council SA (CCSA); Professorial Fellow, Flinders University).

Professor Carlene Wilson (CCSA Chair of Cancer Prevention (Behavioural Science), Flinders University, Flinders Centre for Innovation in Cancer; Visiting Research Fellow, School of Psychology, University of Adelaide).

Research Assistants

Joseph Miller (B. Psychology, Hons) and *Gemma Skaczkowski* (B. Health Sciences, Hons Psychology).

Terminology

Throughout this report the term “Aboriginal” refers to Australian Aboriginal and Torres Strait Islander peoples. The researchers acknowledge that there is no single Australian Aboriginal or Torres Strait Islander culture or group and that there are many diverse communities, language groups and kinships throughout Australia. It is also recognised that Aboriginal and Torres Strait Islander peoples currently live in urban, rural or remote settings, in urbanised, traditional or other lifestyles, and may frequently move between these ways of living.

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MAIN MESSAGES

There is clear evidence of poorer outcomes from cancer in Aboriginal than non-Aboriginal Australians, including an estimated 50% increased risk of mortality for many cancers in the Aboriginal population.

In comparison with non-Aboriginal Australians, Aboriginal people experience a higher incidence of high fatality cancers, more advanced stages of their cancers at diagnosis and greater levels of co-morbid illness. This is frequently coupled with poorer access to care and less comprehensive treatment.

Lower levels of screening participation and a higher prevalence of risky behaviours (e.g., smoking, excessive alcohol consumption, poor diet), would suggest a lack of effectiveness of current interventions. To rectify present disparities, the following areas should be addressed.

Key areas to target to reduce disparities

Data infrastructure

To identify health needs and monitor outcomes of service initiatives, better data are needed, including data from data linkage of cancer registries and administrative databases that include information on Aboriginal status, cancer type and stage, co-morbidity, access to services, treatment type and completeness, patient and family support, and quality of life.

Prevention

Urgent attention is required to reduce high risk behaviours, including those associated with high fatality cancers, and to improve screening participation. Much greater ownership of these endeavours is needed by Aboriginal people, with technical partnerships with Aboriginal and non-Aboriginal researchers.

Programs

A national evaluation strategy is required to assess the impact on Aboriginal health of all cancer control programs. There is a need to include measures of increased access/participation, treatment completeness, and improved quality of life.

Barriers associated with communication/language, differing priorities of health, and psychosocial factors that impact on decision making and participation in cancer control, need to be addressed systematically and evaluated, such that informed judgements can be made on the best strategies to adopt.

Service Delivery

It is very clear that current models of service delivery have not met the needs of Aboriginal people. We recommend a comprehensive review of the best approaches to facilitate and sustain Aboriginal ownership and involvement in all aspects of service delivery.

EXECUTIVE SUMMARY

Background

For non-Aboriginal Australians, marked improvements in all-cancer survival took place in Australia between 1982-1986 and 1998-2004 (Australian Institute of Health and Welfare (AIHW), Cancer Australia (CA) & Australian Association of Cancer Registries (AACR), 2008). However, evidence of great disparity exists for Aboriginal people, with mortality rates estimated to be up to 50% higher for some forms of cancer than seen for non-Aboriginal people (Australian Bureau of Statistics (ABS), 2006; ABS & AIHW, 2008; Cunningham, Rumbold, Zhang, & Condon, 2008).

Scope

Cancer Australia contracted Cancer Council SA (CCSA) to review research and other initiatives aimed at improving cancer control in Aboriginal people. The overall objective of the review was to provide direction for reducing the disparities Aboriginal people experience across the cancer control continuum and thus improving their cancer outcomes.

Methodology

A primary 'national literature' and secondary 'international' search strategy was employed. Data bases searched included: Medline (Ovid/PubMed), Embase, PsycINFO, PsycARTICLES, CINAHL, and Google Scholar. Searches were limited to articles written in English and published since mid-2007, although a number of key review papers published prior to mid-2007 were included to summarise findings for earlier years.

Websites were searched for unpublished reports, and stakeholders acquainted with Aboriginal and Torres Strait Islander cancer control research and research needs were engaged to identify unpublished reports and existing cancer control activities. In response to this review, the investigator team completed a gap analysis to identify key areas of research and/or evidence-based activities in which Cancer Australia might engage.

Discussion

Despite limitations due to inadequate data, the following conclusions can be drawn from the evidence available —

- Aboriginal Australians display higher population-based cancer mortality rates and lower survival rates than non-Aboriginal Australians.
- Aboriginal Australians are more likely to be diagnosed at a more advanced stage of cancer, and are more likely to suffer from high fatality cancers (e.g., cancers of the lung, pancreas, oesophagus, gallbladder, liver and cancers of unknown site).
- Aboriginal Australians display higher smoking rates, hepatitis B carriage, excessive alcohol consumption, and poor diet, and a lower participation in screening programs.
- Higher levels of co-morbid illness, poorer access to treatment, and less complete treatment apply to Aboriginal Australians, which often seem to be aggravated by a lack of appropriate information on cancer and its treatment, and a reluctance to engage with mainstream health services.

- For Aboriginal people, cancer is often seen as a death sentence; is seen as a “white man’s disease”; is regarded as a punishment, curse or a payback; and is often considered to be contagious. Its prevention and treatment are not always regarded as a high priority. Some Aboriginal people see the human body as sacred, and this can influence treatment decisions.
- For Aboriginal people in remote communities, access to palliative care is often hampered by a lack of funds for appropriate equipment, limited information about the types of equipment available, time delays, problems with discharge planning, lack of power sources and electricity, higher transport costs, and the arduousness of long travel. It is difficult to determine the extent of suffering that is endured through poor access to these services.
- Common barriers reported as impacting upon the successful delivery of cancer-related interventions to Aboriginal people include a lack of sustainable funding, difficulties retaining involvement of Aboriginal people in programs, burnout among Aboriginal Health Workers (AHWs), anxiety, communication difficulties, experiences of shame, and transportation difficulties.
- Factors linked with successful programs include: involvement of Aboriginal people in the design and delivery of programs; provision of transport and money for Aboriginal participation; liaison with Aboriginal health services and networks; and good advisory arrangements. Educative programs also appear to benefit from approaches that incorporate scaffolding methods.
- Many programs aiming to reduce disparities in cancer outcomes are underway in Australia. However, few of them have adequate evaluation protocols. The undeniable consequence is that there is a limited accumulation of evidence on the best means for improving outcomes for Aboriginal people.

Conclusion

There is clear evidence of a significant disparity in cancer outcomes in Aboriginal and non-Aboriginal Australians that requires a concentrated research and development effort. This must incorporate appropriate Aboriginal governance if success is to be achieved. Through a sustained research effort, the evidence base must be increased so that real headway can be made in reducing inequalities in outcome in Aboriginal Australians.

Recommendations

In order to reduce disparities in cancer outcome, targeted action is required across four key areas with specific recommendations applicable to each priority area —

Data infrastructure

Recommendation 1: Address the under identification of Aboriginal and Torres Strait Islander status in data registries.

Recommendation 2: Research should be carried out on the variance in Aboriginal cancer-related incidence and survival between urban and remote areas, as well as possible changes in this variance over time.

Recommendation 3: Opportunities to close data gaps through data linkage should be explored, including the linking of registry and administrative databases to assess

effects of early diagnosis initiatives. It is important also to collect data on staging and treatment.

Screening and Prevention

Recommendation 4: Novel approaches to health promotion that are culturally attuned and respect the health and life priorities of Aboriginal communities are required. Piloting and evaluation of culturally sensitive activities designed to address lifestyle choices associated with high fatality cancers is an important priority that requires urgent action. Mainstream approaches coupled with CBPR approaches could be developed and assessed for effectiveness.

Recommendation 5: Further data is required to assess whether participation in cervical screening is increasing and to determine whether a holistic approach to women's health results in increased participation in cervical screening.

Recommendation 6: Increased numbers of Aboriginal workers are required in BreastScreen services and methods of increasing participation should be investigated and assessed for effectiveness.

Recommendation 7: Research into how to integrate Aboriginal cultural beliefs, western medicine and 'bush-medicine' should be conducted.

Recommendation 8: Research should determine culturally appropriate and effective ways of explaining cancer terminology and cancer specific language.

Recommendation 9: Research should be conducted into how Aboriginal people and their health professionals communicate and make decisions about cancer issues.

Programs

Recommendation 10: A comprehensive review of CBPR-based studies should be carried out, with a focus on key factors behind program success or failure. Investigation should also be carried out into the possible appropriateness of research methods other than CBPR.

Recommendation 11: Unpublished program data from current programs should be followed-up, in order to identify factors behind program success or failure.

Recommendation 12: Development of a database to include details of programs for the purpose of monitoring outcomes and identifying factors associated with successful implementation of programs including the impact on health outcomes.

Recommendation 13: A national evaluation strategy of programs across the cancer pathway is required. Although structured evaluations of Aboriginal cancer control programs are needed, there is a need to incorporate the development of a culturally acceptable evaluation model that meets the needs of Aboriginal people. All structured evaluations should integrate assessment of impact on outcomes and thus measures of increased access/participation, treatment completeness and improved quality of life should be included.

Recommendation 14: Conduct a national forum for researchers and health workers to identify barriers and facilitators to successful program implementation, evaluation, and incorporation of appropriate engagement models.

Service Delivery

Recommendation 15: Explore ways to build Aboriginal peoples' confidence in dealing with mainstream health services.

Recommendation 16: Further research could determine methods of engaging Aboriginal people in cancer care and methods of maintaining and up-skilling the existing group of AHWs.

Recommendation 17: Explore clinically effective ways to sculpt the health system to be flexible and adaptive to the needs of urban, regional and remote Aboriginal communities, including identifying mainstream services which are responsive to the needs of Aboriginal people and analysing those models.

Recommendation 18: Research should be carried out into alternative service delivery strategies for remote communities, including the possible use of e-health interventions.

Recommendation 19: Determine the role which Aboriginal controlled health services can play in cancer control and how to support and resource them effectively.

Recommendation 20: Assess the governance structure of mainstream health services for its responsiveness to Aboriginal health service needs and determine opportunities for improvement.

Recommendation 21: Conduct research into improving palliation-related communication for Aboriginal people and identify existing models.

Recommendation 22: Conduct research into the best models for providing cancer support services to Aboriginal people, as well as the best means for providing support services that are culturally appropriate.

Recommendation 23: Identify methods of increasing the number of Aboriginal workers in the area of cancer control including funding positions specific to Aboriginal peoples, training Aboriginal people in all cancer control professions, and perhaps creating a specialist role of 'Aboriginal Cancer Worker'.

Recommendation 24: Evaluate potential methods of improving the cultural sensitivity, responsiveness and approachability of people, systems, and organisations involved in Aboriginal cancer control.

Recommendation 25: To address treatment incompleteness, investigation into the following areas is necessary: the manner in which decisions about treatment options are made, and who makes them; whether the problem of incomplete treatment is more to do with starting treatment, or with completing it; and the nature of the barriers preventing Aboriginal people from completing treatment (as well as ways of reducing their impact).

Recommendation 26: Develop treatment models that engage the Aboriginal community and define health and wellbeing according to community priorities. Objectives will include Aboriginal participation and ownership in service delivery, as well as improving methods of communication concerning cancer, its causes and treatment.

Recommendation 27: Research needs to be conducted into Aboriginal peoples' access to and benefit from rehabilitation services and which approaches will best assist in ensuring follow-up is maintained.

Recommendation 28: Research should be conducted into methods of: improving Aboriginal awareness, perception and information about palliative care; involving Aboriginal people and their families in palliative care decisions; providing effective palliative care in the context of Aboriginal communities.

Recommendation 29: Research should be carried out into what ought to constitute effective palliative care in the context of Aboriginal communities. This should include investigation into the ways in which end of life decisions are made by Aboriginal people, how effectively pain is managed, and methods of incorporating family involvement into mainstream palliative care services for Aboriginal people

Recommendation 30: Funding and training should be directed at the palliative care needs of remote residents, as well as research addressing optimal methods of palliative care service provision in remote communities.

Recommendation 31: Research should be carried out into models that have been successful with Aboriginal people in other areas of chronic disease, with consideration for the possibility of trialling similar models in the context of cancer control for Aboriginal Australians.

RESEARCH REPORT

INTRODUCTION

Background

Aboriginal and Torres Strait Islander people experience great disparity throughout the cancer journey when compared to the general population. The cancer journey is an individual's experience of cancer. It may include screening, detection, diagnosis, treatment, recovery, 'living with cancer' or palliative care. Marked improvements in all-cancer survival took place in Australia between 1982-1986 and 1998-2004 (AIHW, CA, & AACR, 2008) but this has not been observed in Aboriginal populations.

The reported incidence of cancer in Aboriginal and Torres Strait Islander peoples is lower or similar to the general population. However, they are less likely to access early detection programs and medical interventions, resulting in higher morbidity and mortality rates (McGrath & Holewa, 2006; Valery, Coory, Stirling, & Green, 2006). It is important that the disparity in cancer morbidity and mortality experienced by Aboriginal people be addressed by identifying effective and culturally appropriate cancer control measures. Although there is clear evidence of poorer health in Aboriginal people than other Australians, less is known about the most effective preventive and therapeutic strategies for improving cancer control in this population.

Cancer control refers to all actions undertaken by all stakeholders that aim to reduce the burden of cancer on individuals and the community, such as: research; prevention; early detection/screening; treatment; survivorship issues; palliation; education and support for people with cancer and their families; and monitoring cancer outcomes.

Objectives

The Australian Government, through Cancer Australia, aims to minimise the impact of cancer in the community and to improve health outcomes for all people affected by cancer. The overall objective of the project is to improve Aboriginal and Torres Strait Islander cancer control and life expectancy by determining effective and culturally appropriate cancer control measures. Specifically, this project seeks to:

Objective 1: Identify, consolidate and assess the evidence from existing projects and research (quantitative and qualitative), on Aboriginal and Torres Strait Islander cancer control.

Objective 2: Identify and recommend solutions to the barriers and gaps observed in Aboriginal and Torres Strait Islander cancer control.

Objective 3: Identify existing or proposed practical evidence-based activities that Cancer Australia could support to reduce disadvantage in Aboriginal and Torres Strait Islander cancer control.

Objective 4: Identify feasible research opportunities to further develop effective evidence based Aboriginal and Torres Strait Islander cancer control.

Objective 5: Identify other options that may be available to improve Aboriginal and Torres Strait Islander cancer control.

METHODOLOGY

The following approaches were used to identify peer-reviewed literature, grey literature and programs aimed at improving cancer control in Aboriginal people.

Peer-reviewed literature: The investigator team identified review articles published between 2000 and 2007. As the review articles adequately summarised research prior to 2007, additional searches were limited to articles published in English since mid-2007. No other limiters were set. Keywords covered the cancer pathway, incorporating screening/prevention incidence/mortality, treatment, survivorship and palliative care. A more detailed methodology can be found in Appendix A.

The databases searched included Medline (Ovid/PubMed), Embase, PsycINFO, PsycARTICLES, CINAHL, and Google Scholar.

Grey literature and programs: Reports were retrieved from the Australian Indigenous HealthInfoNet, the AIHW and the ABS websites, the Cooperative Research Centre for Aboriginal Health, and the Public Health Information Development Unit. Invitations to submit information on relevant past and present activities/projects involving Aboriginal and Torres Strait Islanders and cancer control were sent to key stakeholders (see Appendix C, table 1) and a snowballing method was applied in order to ensure broad coverage.

A Steering Committee (see Appendix C, table 2) was established to ensure a wide coverage of activities and literature, and to provide feedback on research findings and priority setting.

The investigator team conducted a gap analysis on the completed literature review to identify gaps in current Aboriginal cancer control knowledge and service provision. Based on the identified gaps, the Investigator team then proposed activities and research – grouped by their position in the cancer control trajectory – to address those gaps. The Steering Committee and key stakeholders were provided with the research findings for feedback and priority setting.

RESULTS

Overview

Described in this report are key findings emerging from the detailed literature review and review of programs in cancer control (see Appendix A). Key findings from the literature review are summarised in Part 1 according to their relevance to each stage of the cancer pathway incorporating prevention, screening, diagnosis, treatment, survivorship and palliative care. Key findings from the review of Australian programs aimed at improving cancer control are summarised in Part 2.

Part 1: Review of literature

Prevention/Screening

Although national data were not available for the literature review, there is substantial evidence of an increased representation among cancers in Aboriginals of types that are preventable or amenable to improved outcomes through educative programs and screening. Despite the provision of many services and programs throughout Australia,

little progress has been made to reduce the prevalence of behaviours linked with high fatality cancers prevalent in Aboriginal populations (Condon, Armstrong, Barnes, & Cunningham, 2003). Aboriginal Australians display higher levels of smoking, hepatitis B carriage, excessive alcohol consumption, poor diet, and a lower participation in screening programs.

A 2008 review (Urbis, 2008) of tobacco control in Aboriginal populations noted that although smoking is a priority area in Aboriginal health it is often surpassed by more immediate and pressing issues. The review did not highlight any one intervention likely to result in broad improvements in Aboriginal smoking rates, but instead recommended long term commitment to a variety of interventions. The review emphasised the need for further research and evaluations of health programs, acknowledgement of intermediate outcomes, and service provision that addresses the social environment and norms in order to challenge the acceptability of smoking in Aboriginal communities.

Participation in BreastScreen was lower for Aboriginal women than non-Aboriginal women between 2005 and 2006 (AIHW, 2009), and a smaller proportion of Aboriginal than non-Aboriginal Australians participated in the National Bowel Cancer Screening Program (NBCSP) in 2008 (AIHW & Department of Health and Ageing (DoHA), 2008). As with incidence, mortality, and survival data, participation rates need to be interpreted cautiously due to data quality issues.

Christou et al. (2010) reported that the NBCSP was not reaching many Aboriginal Australians. Factors behind a lower participation of Aboriginal than non-Aboriginal people may have included the reliance on Medicare records for inviting people for screening (resulting in disadvantage for those not enrolled in Medicare), distribution of screening kits by post (leaving out persons without fixed addresses), the nature of the test itself, cultural perceptions of cancer, and a lack of accurate information about bowel cancer and screening.

Little international literature on Indigenous people and cancer prevention has been published since 2007. Erdman (2008) evaluated the Canadian government's Human Papillomavirus (HPV) vaccine program available for girls from grades 6 to 8. Erdman suggested that many parents, including those from traditionally conservative Canadian Aboriginal communities, may be reluctant to acknowledge the possibility of their child being vulnerable to a sexually transmitted illness. The Canadian strategy has been to avoid some of the stigma around HPV infection by calling the vaccine a "cancer vaccine". Although this strategy may serve to increase vaccination rates, it may also pose ethical problems, including the creation of a false perception of risk, potentially leading to an inequitable distribution of the vaccine according to actual risk levels (Erdman, 2008).

A HPV vaccine program for Australian Aboriginals is currently in operation (Menzies & Singleton, 2009), and Erdman's concerns in relation to the Canadian program may bear relevance to the Australian context.

Many barriers to screening have been documented with international Indigenous communities, including anxiety; a sense of fatalism regarding cancer; poor communication from health providers, including an over-reliance on medical terminology; gender of health provider; number of people in the screening room; embarrassment; shame; transport issues; lack of financial support; health care

system disorganisation; lack of screening awareness; desire to appear strong; misconceptions about risk factors; and culture-specific beliefs.

Studies conducted with Native Hawaiians, Native Americans, and Canadian Aboriginal people suggest that participants preferred material with clear, simple wording and illustrations. In addition, participants noted a preference for messages to be designed to accord with their community beliefs and spiritual values; to appropriately address cancer-related anxiety, embarrassment, or discomfort; to account for the diversity between and within Indigenous communities and the need to treat each community separately; and to take note of the relevance of particular cancers to the communities involved.

Screening promoters have also been recorded in some detail, including: placing a high level of importance on the breast, high self-efficacy, exposure to strong group norms, agreement with the efficacy of mammography, high perceptions of cancer severity, encouragement from chiefs and pastors, receipt of appointment slips, transport assistance, appropriate gender of health provider, encouragement, support, and cancer-related anxiety. Bearing in mind that these barriers and promoters are properties of specific cultures, they may or may not be relevant to Aboriginal people in Australia.

A pilot mammography intervention for Navajo Indians in New Mexico (English et al., 2008) was successful for those who participated, and a colorectal cancer screening program for Alaska Native people significantly increased participation rates (Redwood et al., 2009). An evaluation of the factors that rendered these projects successful might constructively inform current and future screening programs in Australia.

Community Based Participatory Research (CBPR) programs have been applied in Hawaii, New Zealand and Samoa with mixed success (Mishra, Luce, & Baquet, 2009; Kobetz et al., 2009). CBPR incorporates a range of methodologies embodying a commitment to involve community members, with representatives from community organisations working in partnership with researchers in the design and implementation of research (Minkler, 2005; Israel, Eng, & Schulz, 2005; Israel, Shulz, Parker, & Becker, 1998). Reasons for the mixed success are not clear and it may be a result of differences in the application of the CBPR approach.

Diagnosis

Incidence/Mortality data

Based on current evidence, Aboriginal Australians experience similar or somewhat lower incidence rates for all cancers combined than other Australians, (ABS & AIHW, 2008; ABS, 2006). However, for many cancers higher mortality rates (exceeding 50%) have been reported for Aboriginal people (ABS & AIHW, 2008; ABS, 2006; Cunningham et al., 2008).

Mortality rate: A measure of the number of deaths in a population, conventionally reported as an annual rate per 100,000.

Crude survival rate: The proportion of people alive at a specified point in time following the diagnosis of a particular disease.

Relative survival rate: A measure of the percentage of patients with a particular disease who remain alive after a specified interval (usually five years) following diagnosis, divided by the expected survival of the general population.

Research conducted between 2000 and 2004 found that Aboriginal males experience higher incidence rates than non-Aboriginal males for cancers of the lung, unknown primary site, oesophagus, liver, stomach, pancreas, and Aboriginal females experienced higher incidence rates than non-Aboriginal females for cancers of the lung, unknown primary site, cervix, uterine body and ovary (Roder & Currow, 2009).

Between 2002 and 2006, other research has reported that ovarian cancer incidence, survival, and mortality were not significantly different for Aboriginal and non-Aboriginal females (AIHW, 2010). Aboriginal people had lower incidence rates for breast cancer between 2002 and 2006, but also lower five-year crude survival estimates. However, it should be borne in mind that these survival estimates were for death from any cause, not breast cancer specifically. The mortality rate for breast cancer did not differ significantly by Aboriginal status, despite the lower breast cancer incidence reported in Aboriginal women (AIHW & National Breast and Ovarian Cancer Centre (NBOCC), 2009). Reliable data were only available for Queensland, the Northern Territory, Western Australia, and South Australia for this research.

Differences in cancer mortality are partly explained by differences in distribution of cancer type between Aboriginal and non-Aboriginal Australians; incidence rates for the most common “lower fatality” cancers (e.g., cancers of the breast, prostate, colon/rectum, and skin) tend to be lower in Aboriginal people whereas rates for “high fatality” cancers (e.g., cancers of the lung, pancreas, liver, gallbladder, and mouth/pharynx/oesophagus) tend to be higher (ABS & AIHW, 2008).

Although there has been a substantial increase in the Aboriginal cancer control literature, particularly between 2003 and 2008, this tends to be at a local level, with a lack of national Aboriginal cancer statistics due to a continuing inadequacy of identification data (Stumpers & Thompson, 2009).

Other data and approaches to measuring disparities

The AIHW and ABS have produced several key reports on the health and wellbeing of Aboriginal people. Fundamental to presentation of data are efforts to consider the social determinants of health and wellbeing and how these determinants impact on the data reported. Key determinants of health identified include: education, employment, housing and housing effects (e.g., overcrowding), sanitation facilities, and isolation and remoteness of residence from mainstream services. On all measures, Aboriginal people show significantly poorer characteristics (ABS & AIHW, 2008).

Lower socio-economic status (SES) and broader background factors such as cultural marginalisation and poor living conditions associated with lower SES may also impact on cancer outcomes (ABS & AIHW, 2008; Cunningham et al., 2008). For example, approximately 14% of Aboriginal households are reported to be

overcrowded, with inhabitants living in poorly-maintained dwellings with inadequate access to services (ABS & AIHW, 2008).

The utility of traditionally used measures such as disability-adjusted life years (DALYs) and quality-adjusted life years (QALYs) as measures of health system performance for Aboriginal people has recently been questioned. The AIHW, in consultation with Aboriginal communities, developed a measure of community functioning incorporating the following domains: power to control choices and options; connectedness to family land and history; health status; presence of chronic disease and substance abuse; culture; identity; continuing employment; education; infrastructure and community; coping within the internal world and external world; structure and routine; and, income (ABS & AIHW, 2008).

Treatment

Research suggests that in general, the further residences are located from a major treatment centre, the poorer the cancer outcome (Heathcote & Armstrong, 2007). At the 2001 Census, 26% of Aboriginal and Torres Strait Islander people lived in Remote or Very Remote areas, compared to 2% of non-Aboriginal Australians (ABS, 2005).

A number of factors other than geographic remoteness, which may contribute to poorer cancer outcomes among Aboriginal people, have been investigated. There is clear evidence of contributions to poorer outcomes from an excess of more lethal cancer types in Aboriginal people (Roder & Currow, 2009) and also evidence of more advanced stages at diagnosis, incomplete treatment (Shahid, Finn, & Thompson, 2009) and higher levels of co-morbidity (Valery et al., 2006; Condon, Barnes, Armstrong, Selva-Nayagam, & Elwood, 2005).

Newman et al. (2008) noted that treatment choices could be influenced by a range of non-clinical factors, including difficulties travelling to specialist clinics for treatment, alienation of Aboriginal patients in major hospitals, factors in the broader context of Aboriginal people's lives such as the presence of other chronic diseases, differences in Aboriginal people's perceptions of health, and obligations of Aboriginal people to perform a range of social and domestic roles.

Stumpers and Thompson (2009) described potential service barriers to Aboriginal engagement with cancer services as consisting of: incomplete information about cancer; remote living and transportation difficulties; a lack of suitable, culturally-sensitive services; and a number of personal issues centring on anxiety and financial difficulty.

Psychosocial factors potentially linked with incomplete treatment have been highlighted in qualitative research, although the evidence for the role they play in treatment incompleteness is not definitive because of difficulties with sample size and representativeness. Newman et al. (2008) stressed the importance of acknowledging and taking account of cultural differences between Aboriginal and non-Aboriginal people, and the great diversity of culture across the Aboriginal population. Nevertheless, Shahid and Thompson (2009) concluded that, in general, treatment incompleteness was associated with fatalistic beliefs about cancer outcomes; perceptions of cancer as a "white man's disease", a curse or punishment; the belief that cancer is contagious; and a higher concern about other health and non-health issues.

Following in-depth interviews with Aboriginal people affected by cancer from across Western Australia, Shahid et al. (2009) and Thompson et al. (2006) identified several service barriers, including negative Aboriginal perceptions of the western health system, frequent staff turnover, the need for Aboriginal support workers, delays and poor staff communication, difficulty navigating hospitals, practical issues (including issues related to money, accommodation, transportation, community responsibilities, and child care needs), and the need for hospital treatment to be better connected with the Aboriginal community. With these barriers in mind, the researchers recommended case conferencing between cancer specialists and primary care providers, ensuring the support of a family member to assist patients, developing and improving access to effective and culturally appropriate primary care, and an effort to engage Aboriginal people in cancer service planning.

Shahid et al. (2009) also interviewed cancer patients, family members of people who had died from cancer, and Aboriginal health care providers. These interviews suggested that attitudes toward cancer services could be improved by adoption of a culturally respectful stance. Service providers should accept that traditional healing and bush medicines can be important in encouraging Aboriginal people to be involved in western medical treatment.

McGrath, Ogilvie, Rayner, Holewa and Patton (2005) emphasised the importance of providing complete, intelligible information to Aboriginal patients and appropriate members of their family networks, as dictated by Aboriginal cultural beliefs and practices. McGrath and Patton (2007) found that for many Aboriginal patients, relocation was associated with loneliness; emotional distress relating to separation from family; financial distress; difficulties involving travel and accommodation; and fears related to disempowerment, cultural alienation, the western health system, travel, language barriers, and different communication patterns.

Palliative Care/Survivorship

In Australia, the provision of supportive care across the cancer trajectory is indicated as best practice in cancer care (Clinical Oncological Society of Australia (COSA), Cancer Council Australia (CCA), & National Cancer Control Initiative (NCCI), 2003). In the Optimising Cancer Care framework (CCA & NCCI, 2003, p. xvii), it is emphasised “[t]hat the needs of special populations, especially Aboriginal peoples, be the focus of special efforts to bridge the current gaps in access to and utilisation of culturally sensitive cancer services.”

Currently, little is known about the preferences of Aboriginal people for support throughout diagnosis, treatment and into palliative care or survivorship. Some observations relating to the provision of palliative care in rural and remote Australia can be drawn from qualitative studies performed in this area. According to McGrath, Holewa and McGrath (2007), the provision of palliative care in remote communities is often hampered by a lack of funding for appropriate equipment, limited information about available equipment, time delays, ineffective discharge planning, lack of electricity, higher transport costs, and the arduousness of long distance travel.

Kelly and Minty (2007) undertook a literature review that indicated a wide variety of beliefs about end of life issues among Canadian Aboriginal people. Several common themes emerged, including respect, trust and family involvement. Subthemes focussed on barriers pertaining to language, communication, spiritual beliefs, geography and

finance. Mokuau and Braun (2007) conducted a focus group with Native Hawaiian cancer survivors and families of cancer survivors. Participants generally agreed that family counselling in the medical office would be beneficial, especially if information was provided on the stages of cancer, treatment options, the healthcare system, and resources available for survivors and caregivers. They also stated that they would have benefited from the provision of medical and other literature, as well as outreach and home-visiting services, including education on how to support cancer survivors.

Mokuau, Braun, Wong, Higuchi and Gotay (2008) conducted a pilot study on the feasibility of a family intervention for Native Hawaiian women with cancer. For the intervention group, medical social workers provided cancer survivors and their family-members with six information sessions focussed on topics such as information-seeking, communication with healthcare providers, and reorganising housework. Members of the control group received only two sessions. Women with cancer in the intervention group exhibited improved coping and decreased distress and family members in the intervention group exhibited improved self-efficacy and coping following the intervention.

Western Australian researchers have explored how cultural beliefs impact on the experience of Aboriginal people with cancer support services in the hospital setting (Shahid et al., 2009; Shahid & Thompson, 2009). Contextual barriers included poor expectations due to experiences with racism and discrimination – for example, when interacting with some doctors – lack of flexibility within the hospital environment for dealing with the needs of the extended family, failure to understand the importance of dying within the community, the apparent difficulty of implementing treatment regimens within the home community, the necessity of culturally inappropriate interactions between the sexes in the hospital, and unmet desires to interact more with AHWs. Communication barriers identified included a lack of interpreters, failure of medical staff to effectively communicate (linked with a failure to establish an ongoing personal relationship), and a belief that staff were not empathetic or compassionate enough. Together these barriers often led to distrust in cancer treatment services.

McGrath and Patton (2007) emphasise the importance of delivering palliative care in a culturally-appropriate way. McGrath and Holewa (2006) proposed principles for the provision of palliative care to Aboriginal people, namely: equity, autonomy, empowerment, trust (humane and non-judgmental care), seamless care, an emphasis on living, and cultural respect. McGrath and Holewa (2007) argued that interpreter and cultural liaison services were essential in the provision of palliative care for Aboriginal people. McGrath, Holewa and McGrath (2007) described a range of impediments and barriers to the provision of palliative care in rural and remote regions of the Northern Territory. Practical obstacles included lack of funds for clinics to provide appropriate equipment, limited knowledge of the types of equipment available, time delays, problems with discharge planning, lack of electricity or unreliable power sources, high costs of power, high transport costs, and issues around geographic location and mode of transport, harsh weather, and arduousness of long travel for sick people.

The multiplicity of spiritual backgrounds and perspectives of health and illness are also important considerations for culturally-appropriate research (McGrath & Phillips, 2008b; McGrath & Phillips, 2008a). McGrath (2010) proposed the 'Living Model' to address Aboriginal palliative care barriers, outlining 12 key processes across four key

areas including community participation, empowerment, choice and personal advocacy. McGrath emphasised the importance of communication, family involvement, cultural appropriateness of services, avoiding relocation, and the involvement of AHWs. Communication, facilitated by the employment of workers from within the same cultural group, was identified as a key factor in working with cultural groups (Huang, Yates, & Prior, 2009).

Part 2. Review of National Programs

A range of programs and activities that aim to improve cancer control for Aboriginal people was identified. The majority of programs involved cancer education, tobacco control, smoking cessation, and screening. A smaller number of programs focussed on treatment, research into Aboriginal perceptions of cancer, and support. Few incorporated evidence-based or theoretically driven approaches, and few were evaluated using evidence-based methodologies. CBPR was commonly reported as a preferred philosophy for working with Aboriginal communities. At times a claim to utilise CBPR appears to have been used to justify an ad-hoc approach to interventions. Consequently, the extent to which this methodology is useful in this setting remains largely untested. Similarly, the extent to which this methodology promotes adequate consultation and/or participation of Indigenous people in research and its governance is largely undocumented.

Tobacco Control/Smoking Cessation

Thirty-seven programs were identified that addressed tobacco control or smoking cessation. Specifically, these involved resource development (15 programs); promotion and awareness-building (14 programs); AHW training and education (13 programs); general training and education (11 programs); treatment, including provision and subsidisation of Nicotine Replacement Therapy (NRT) (9 programs); interventions (8 programs); education and training for general health staff and General Practitioners (6 programs); support (5 programs); grants and financial support to other programs (4 programs); data collection and research (3 programs); event sponsorship (3 programs), and a wide-scoped approach incorporating interventions, education, support for health professionals, and legislation (1 state government plan).

Outcomes were rarely recorded, making it difficult to determine which approaches were most effective. At times the absence of recorded outcomes was related to an absence of continued funding required to complete the project. A small number of programs reported successful outcomes, and these had adopted at least one of the following methods: training AHWs, facilitating Quit support groups, providing free NRT, adopting a CBPR methodology, and implementing a culturally-appropriate Quit program. Of these tactics, Quit support groups, free NRT, and culturally-appropriate Quit programs were all adopted more than once in successful tobacco control and smoking cessation programs. However, the small number and low quality of program evaluations should be borne in mind when considering these findings.

Education

Of the 15 education programs and activities identified, eight were training programs for AHWs, two involved the development of education resources, two were community education sessions, and one involved the provision of education resources to health professionals in rural and remote areas. Outcomes were generally recorded

poorly, if at all. A number of training workshops for AHWs resulted in improvements across a range of confidence indicators (e.g. “I can discuss the impact of a cancer diagnosis with the patient”), but the factors behind these improvements were not evident from the information available.

Screening

Eight screening programs were identified, four of which exclusively targeted Aboriginal people. Four programs provided mobile screening services to Aboriginal people, and one provided free transport to allow access to screening services. At least one of the following methods was adopted by programs that reported improved screening participation: liaising with Aboriginal health services and communities, funding free transport and promoting it, organising block bookings for Aboriginal people, participating in seminars for AHWs, participating in Aboriginal women’s health days/camps, educating GPs, employing full-time AHWs, providing a mobile screening service, allowing access to services on diagnosis, and prior provision of health education and promotion information.

Treatment

One program relating to cancer treatment was identified. This was the employment of an Aboriginal Cancer Care Coordinator (ACCC) in New South Wales. While there is some evidence that the ACCC was beneficial in developing links within Aboriginal health services and mainstream cancer services, a more detailed evaluation would be required to determine the precise impact on treatment outcomes.

Perceptions

Two research programs investigated Aboriginal people’s cancer-related perceptions. One of these addressed cancer, cancer services and treatment, and rural-urban differences, and the other was involved in the development and testing of information materials to encourage adolescent Aboriginal females to be vaccinated against HPV. The first study found that fear of death, fatalism, shame, preference for traditional healing, beliefs such as “cancer is contagious”, and other spiritual issues affected the decisions of Aboriginal people whether to access cancer services. Several other practical issues also affected Aboriginal patients not being interested in accessing services and treatment facilities, including problems during communication with doctors, lack of support, inappropriate hospital setting, travel cost, transport and lack of appropriate city accommodation. As part of the CBPR methodology, and arising directly out of the research project, support was provided to initiate and support an Indigenous Women’s Cancer Support Group (IWCSG) in Geraldton, Western Australia.

Support

Four Aboriginal cancer support programs were identified. Two of them involved the facilitation of support groups for Aboriginal women with cancer, one involved the development of an Aboriginal cancer support and information resource, and one was a research project investigating Aboriginal supportive care needs and piloting an Indigenous Patient Navigator. Outcomes were only reported for one program, the IWCSG, which received a favourable evaluation from the Centre for International Health at Curtin University. As well as providing the opportunity for group

interactions between patients, the IWCSG program was involved in: providing cancer education for health service providers, patients and carers; providing opportunities for non-Aboriginal health service providers to have Aboriginal input into the care and support of Aboriginal women with cancer; and, offering support through a 'grapevine' or 'bush telegraph', where cancer patients and carers are contacted and supported by IWCSG members.

Other General Health Programs

Nine general health programs and/or plans with a focus on Aboriginal Australians were identified. Two were clinic-based programs addressing chronic disease and sexual health through the provision of regular clinics, education, screening, and health promotion. Two were auditing programs focussing on chronic disease services for Aboriginal Australians. One was an online training package for health workers, including AHWs. One covered community-based health promotion. Three government plans addressed Aboriginal healthcare broadly. Two of the government plans have reported positive outcomes, including a number of service improvements and funding provision for one hundred health services.

Barriers

Barriers to implementation were not always easy to assess, in part because many programs were still in progress at the time of writing, and often because very little information was available. A lack of sustainable funding was commonly reported as impacting upon the successful delivery of interventions. Most projects relied on one-off grants to pursue particular projects, which was problematic when further phases were required. Other barriers included the difficulty of retaining Aboriginal people in programs; AHW burnout; and a lack of understanding between mainstream health services and Aboriginal health services, with the latter not always considering cancer to be a health priority. In programs coordinated by Cancer Council Western Australia, factors linked with the successful promotion of programs included the provision of funding to assist with travel; effective regional networks; good advisory contacts, and Aboriginal involvement in the development and delivery of programs. Unfortunately, a lack of documented information concerning the effectiveness of interventions in other regions such as the Northern Territory, precludes the analysis of factors predicting successful outcomes across states and territories. Nevertheless, in the Northern Territory a barrier identified as impacting upon access to gynaecological services was the reliance on one specialist travelling for limited appointments.

DISCUSSION

A review of key findings and gaps identified by the investigator team are presented (Objective 1) together with recommendations on how further evidence could be acquired to address these gaps (Objective 2). Specific solutions to address gaps include recommendations to improve data infrastructure and to support a national evaluation of programs (Objective 3) as well as recommendations for a comprehensive research and development program focused on these issues (Objective 4). Other recommendations are for research and development of methodologies for targeting gaps in prevention and service delivery, including mechanisms for addressing psychosocial factors across the cancer pathway (Objective 5).

Data Infrastructure

The majority of Australian peer-reviewed literature and reports focussed on incidence and survival rates. Overall, lower case survivals and/or higher population-based cancer mortality rates were found in Aboriginal than non-Aboriginal Australians. In these studies, possible factors contributing to survival shortfalls were reported to include less comprehensive treatment and higher levels of co-morbidity.

Aboriginal people are diagnosed with more advanced disease, although data on stage at diagnosis are not available from most cancer registries, limiting opportunities to assess effects of interventions. Fewer Aboriginal than non-Aboriginal people undertake and complete curative treatment but data on cancer treatment are only available from specific research studies and thus reasons for the disparity and differences over time are difficult to identify. At present cancer registration data on Aboriginal status are incomplete, although the level of under identification is unknown for most registries and addressing this issue is a priority.

Recommendation 1: Address the under identification of Aboriginal and Torres Strait Islander status in data registries.

The Aboriginal population is not a homogeneous population and there is little information about variations within the Aboriginal population in cancer incidence and outcomes or on changes in these across time. For many aspects of cancer control, the data are of variable quality thereby compromising comparisons between Aboriginal and non-Aboriginal populations and also potentially between Aboriginal communities (e.g., rural and urban). Nonetheless, the limited data we do have indicate that Aboriginal people have a different pattern of cancer incidence, experience more high-fatality cancers (that are mostly preventable), and lower cancer survival than non-Aboriginal people.

Recommendation 2: Research should be carried out on the variance in Aboriginal cancer-related incidence and survival between urban and remote areas, as well as possible changes in this variance over time.

Urgent attention is required to ensure that jurisdictional data in cancer registries and administrative data on cancers in Aboriginal people are collected in a consistent manner with adequate descriptors of Aboriginal status for meaningful geographic and secular comparisons. This is a crucial requirement if there is to be population health and health-services research that effectively addresses the needs of Aboriginal people. In addition to the collection of data on Aboriginal status, data on staging and treatment are needed.

Recommendation 3: Opportunities to close data gaps through data linkage should be explored, including the linking of registry and administrative databases to assess effects of early diagnosis initiatives. It is important also to collect data on staging and treatment.

Screening and Prevention

Despite the prevalence of high fatality cancers in the Aboriginal population that are preventable, virtually no peer reviewed research with a focus on primary prevention targeting lifestyle factors (e.g., diet, smoking, and excess alcohol consumption) in Aboriginal people was identified. Some federal programs focussing upon ‘general health’ were identified. However, the applicability of mainstream health promotion campaigns (e.g., Go for 2 and 5; How do you Measure Up?) to Aboriginal people, and their success in moderating lifestyle risk factors in Aboriginal communities, have not yet been determined. Indeed, primary preventive efforts are highly focused on mainstream community values, opportunities, constraints and circumstances and thus, it is likely that their impact on Aboriginal people will be limited. Novel approaches to health promotion and subsequent cancer prevention are required. These approaches need to be culturally attuned, relevant, and acknowledge and respect the health and life priorities of the Aboriginal communities. Piloting and evaluation of culturally sensitive activities designed to address lifestyle choices is an important priority that requires urgent address. Potential theories of behaviour modification should be investigated for cultural acceptance and applicability to Aboriginal people.

Similarly, reliance on mainstream social marketing programs to reduce smoking among Aboriginal people is yet to be established as an effective approach despite high levels of efficacy in the non-Aboriginal community. By contrast, tobacco control and smoking cessation programs that adopt CBPR-guided methodology have been shown to be effective, and culturally-tailored Quit-style programs developed in Aboriginal communities have been effective in some instances.

An evidence-based amalgam of mainstream social marketing and CBPR approaches could be developed and might prove effective, but the data on their effectiveness are yet to be collected.

Recommendation 4: Novel approaches to health promotion that are culturally attuned and respect the health and life priorities of Aboriginal communities are required. Piloting and evaluation of culturally sensitive activities designed to address lifestyle choices is an important priority that requires urgent action. Mainstream approaches coupled with CBPR could be developed and assessed for effectiveness.

Screening and Prevention Programs

Programs for Aboriginal cancer control have focussed on cancer education, tobacco control, smoking cessation, and screening. However, generally a lack of methodological rigour precludes recommendations to support any particular programs to reduce disadvantage.

Encouraging participation in cancer screening is an important goal of reducing cancer incidence and morbidity among Aboriginal Australians. Participation in cervical screening programs is generally estimated to be lower for Aboriginal than for non-Aboriginal women (although higher than national rates have been achieved in some regions, for example, in the Top End, although the precise factors behind this are not clear (Binns & Condon, 2006)). The precise rate of Aboriginal participation in cervical screening programs is not known, due to low data quality and the lack of

recording of Aboriginal status on cervical screening registries. If Aboriginal status data were collected on pathology request forms, this information could be included in cervical screening registries. Research is needed into cervical screening participation by Aboriginal women to assess whether participation is increasing (as suggested by decreasing cervical cancer incidence) and whether a holistic approach to women's health results in better cervical screening participation.

Recommendation 5: Further data is required to assess whether participation in cervical screening is increasing and to determine whether a holistic approach to women's health results in increased participation in cervical screening.

BreastScreen participation is lower for Aboriginal than other Australian women (AIHW, 2009). Numbers of Aboriginal workers in BreastScreen services should be increased and methods investigated for improving Aboriginal screening participation rates. Aboriginal participation in bowel cancer screening has also been lower than non-Aboriginal participation. This may be explicable in terms of the prioritisation of cancer within the lives of Aboriginal communities, service barriers associated with remoteness, and/or the cultural appropriateness of service models.

Recommendation 6: Increased numbers of Aboriginal workers are required in BreastScreen services and methods of increasing participation should be investigated and assessed for effectiveness.

Screening programs that adopt the following processes have returned good outcomes: prior provision of educational resources, providing access to services upon diagnosis, arranging follow-up care and ongoing support, collaborating with Aboriginal health bodies and services, providing transportation assistance, educating GPs, employing full-time AHWs, and engaging in a range of promotional activities.

An HPV vaccine program for Australian Aboriginal people is currently in operation and is investigating knowledge and attitudes affecting uptake of HPV vaccination for Aboriginal females aged 13-26 years. Hepatitis B is more prevalent among Aboriginal than non-Aboriginal Australians. In response, hepatitis B vaccination coverage is reported to be high among Aboriginal children. It should be determined whether any lessons can be learnt from vaccination programs in promoting other aspects of cancer control. Meanwhile the universal vaccination program should be effective in ensuring continued levels of hepatitis B vaccination coverage for Aboriginal children.

Psychosocial factors

A small number of studies addressed psychosocial factors which may be relevant across each phase of the cancer pathway from cancer prevention, screening, support to survivorship/palliative care. A subset of articles mainly by McGrath et al. focussed on palliative care and another subset of articles focussed on attitudes and beliefs about cancer in Western Australia. While these findings may be valid for the particular cultural group studied, it is not possible to generalise with any confidence these findings to other Aboriginal cultural groups in Australia. Nevertheless there were common themes identified in these studies. Many Aboriginal people have a fatalistic view of, and misconceptions about, cancer (e.g., that cancer is contagious, or a curse), which seem more akin to the broader Australian misconceptions in the 1950s.

It is not presently known whether these misconceptions are widespread. Investigations should be conducted into ways that Aboriginal people can become more accurately informed about cancer, as well as addressing which strategies have changed perceptions about cancer in the general community over the past several decades, and whether these strategies might be successfully adapted for Aboriginal people in a culturally-appropriate way. Research into what constitutes an appropriate blend between Aboriginal cultural beliefs, western medicine and use of 'bush-medicine' should be conducted, bearing in mind that the answer may not be the same for all Aboriginal peoples.

Recommendation 7: Research into how to integrate Aboriginal cultural beliefs, western medicine and 'bush-medicine' should be conducted.

Aboriginal people have a greater socio-economic and disease burden, and other social and cultural demands that affect their priorities in personal health decisions. It is not yet known whether a holistic approach to decision-making would lead to better cancer outcomes for Aboriginal people. Research should be conducted into how Aboriginal people and their health professionals communicate, and make decisions about, cancer issues.

Recommendation 8: Research should determine culturally appropriate and effective ways of explaining cancer terminology and cancer specific language.

Aboriginal people want more family involvement in decisions about cancer. However, most cancer professionals do not know how to interact with the extended families of Aboriginal patients, including which family members have authority to make decisions. Methods by which health professionals can better understand and become more competent in dealing with Aboriginal people and their families should be studied.

Recommendation 9: Research should be conducted into how Aboriginal people and their health professionals communicate and make decisions about cancer issues.

Program Evaluation

CBPR is commonly used internationally in developing interventions for Indigenous cancer control and is often recommended as the best approach. It is unclear, based on published reports, whether this approach has always been appropriately applied nationally, and a comprehensive review of studies using CBPR is required. Furthermore, follow up of unpublished program data from current programs should be conducted in order to determine key factors associated with program success or failure. Investigation into the possible appropriateness of other research methods should also be carried out.

Recommendation 10: A comprehensive review of CBPR-based studies should be carried out, with a focus on key factors behind program success or failure. Investigation should also be carried out into the possible appropriateness of research methods other than CBPR.

Work is required to follow-up, on an ongoing basis, program activities in order to identify factors linked with effective programs. In addition, to facilitate the collection of appropriate data, it may be feasible to engage in structured evaluations of Aboriginal cancer control programs to assess effectiveness across a range of items, including (as appropriate) changes in cancer outcomes, cost-effectiveness, sustainability, engagement with the community and community-determined goals, and facilitation of governance by the Aboriginal groups involved.

Recommendation 11: Unpublished program data from current programs should be followed-up, in order to identify factors behind program success or failure.

Program information could be recorded on a national database and complemented by a national evaluation strategy to ensure that programs are evaluated in a structured manner using culturally appropriate methods. Data should be collected on indicators of improvement (e.g., more complete treatment, higher participation in screening programs and prevention activities, improved support and potentially higher quality of life). Ideally, associated evaluation data would be linked to population level data sets including data on incidence and mortality to optimise the evidence base.

Recommendation 12: Development of a database to include details of programs for the purpose of monitoring outcomes and identifying factors associated with successful implementation of programs including the impact on health outcomes.

Within the current review, there may be some programs for which it would be feasible to develop and pilot an evaluation strategy with the view to expanding to other cancer control programs across the cancer trajectory. Such an approach would need to consider developing an evaluation model that was culturally acceptable and met the needs of Aboriginal people (see McDonald, Priest, Doyle et al., 2010).

Recommendation 13: A national evaluation strategy of programs across the cancer pathway is required. Although structured evaluations of Aboriginal cancer control programs are needed, there is a need to incorporate the development of a culturally acceptable evaluation model that meets the needs of Aboriginal people. All structured evaluations should integrate assessment of impact on outcomes and thus measures of increased access/participation, treatment completeness and improved quality of life should be included.

It is important to note that the programs information presented in this report is incomplete and where barriers have not been identified, it should not be assumed that there are none. It may be beneficial to conduct a national forum where people involved in program design and implementation can identify and discuss barriers.

Recommendation 14: Conduct a national forum for researchers and health workers to identify barriers and facilitators to successful program implementation, evaluation, and incorporation of appropriate engagement models.

Service Delivery

Many Aboriginal people are wary of hospitals and other mainstream services, and research needs to explore means whereby Aboriginal people can become more confident dealing with mainstream services.

Recommendation 15: Explore ways to build Aboriginal people's confidence in dealing with mainstream health services.

Generally, there has been inadequate participation in and ownership of cancer health services by Aboriginal people outside the realm of community-controlled health services. There have been inadequate numbers of Aboriginal care coordinators/navigators/health workers at hospital and community levels of care and uncertainty about the best models to pursue to involve Aboriginal people in service governance arrangements.

Recommendation 16: Further research could determine methods of engaging Aboriginal people in cancer care and methods of maintaining and up-skilling the existing group of AHWs.

Responsive Health System

There is a need for a health system that is flexible and adaptive to the needs of Aboriginal communities. While there are some examples of work being done in this area, these efforts tend to be directed at motivations of individuals rather than taking a whole-system or hospital-based approach. Further research is required to determine factors associated with responsive health systems.

Available and Approachable Services

Except in remote areas, Aboriginal people comprise a very small proportion (2% or less) of the clientele of most cancer services and it is yet to be understood how mainstream services can provide both a clinically effective and culturally appropriate service to Aboriginal people. Mainstream services vary in their level of responsiveness to Aboriginal people, but the reason for this variance is not fully understood. Research should be conducted into ways mainstream services can become sensitive and responsive to Aboriginal clients. This may be best undertaken by identifying mainstream services that have a reputation as responsive to the needs of Aboriginal people and assessing their characteristics.

A high proportion of the Aboriginal population live in remote areas from which cancer services are not easily accessible, and the best method of making services accessible to people in remote areas is yet to be determined. The potential for novel e-health interventions to play an increasingly important role should be considered as

well as research that identifies alternative strategies for remote communities, including outreach services, and holistic services.

Recommendation 17: Explore clinically effective ways to sculpt the health system to be flexible and adaptive to the needs of urban, regional and remote Aboriginal communities, including identifying mainstream services which are responsive to the needs of Aboriginal people and analysing those models.

Recommendation 18: Research should be carried out into alternative service delivery strategies for remote communities, including the possible use of e-health interventions.

Governance

Many Aboriginal people are more comfortable with organisations run by Aboriginal people; however, health care services run by Aboriginal people are over-burdened and under-resourced. The extent to which these types of health care services can become more involved in cancer control needs to be investigated, as well as possible methods in which this could be achieved, the supports and resources that would be required to achieve it, and likely effectiveness.

Recommendation 19: Determine the role which Aboriginal controlled health services can play in cancer control and how to support and resource them effectively.

The extent to which the governance structure of mainstream health services influences its responsiveness to Aboriginal people is yet to be determined. Research should be conducted into possible changes to the governance structure and how this might improve service responsiveness to Aboriginal people.

Recommendation 20: Assess the governance structure of mainstream health services for its responsiveness to Aboriginal health service needs and determine opportunities for improvement.

Communication

Communication, respect, and family involvement in decision making and care are important in establishing trust in palliative services. Research should be carried out into ways of improving palliation-related communication for Aboriginal people.

Recommendation 21: Conduct research into improving palliation-related communication for Aboriginal people and identify existing models.

Supportive care

There is a need for support for Aboriginal patients and their families across the cancer control spectrum. Aboriginal people (professionals and survivors) should be involved

in providing this support, with training and employment in cancer support services being provided for Aboriginal people.

Recommendation 22: Research should be conducted into the best models for providing cancer support services to Aboriginal people, as well as the best means for providing support services that are culturally appropriate.

Workforce

There are currently insufficient numbers of Aboriginal workers in cancer services, and more needs to be known about the best models for attracting, training, and retaining Aboriginal people as cancer workers. It should be borne in mind, however, that research on Aboriginal health workforce development is beyond the scope of this project and the role of Cancer Australia. Possible methods of increasing the number of Aboriginal workers in the area of cancer control include funding positions specific to Aboriginal peoples, training Aboriginal people in all cancer control professions, and perhaps creating a specialist role of ‘Aboriginal Cancer Worker’. This could be taken up by Cancer Australia.

Recommendation 23: Identify methods of increasing the number of Aboriginal workers in the area of cancer control including funding positions specific to Aboriginal peoples, training Aboriginal people in all cancer control professions, and perhaps creating a specialist role of ‘Aboriginal Cancer Worker’.

It has also been noted that some health professionals are not approachable by Aboriginal people and lack cultural sensitivity. Cultural effectiveness training is available, but it is not clear how effective this is in changing behaviour, systems and organisations, and further investigation should be carried out into ways in which people, systems and organisations can become more responsive and approachable to Aboriginal clients.

Recommendation 24: Evaluate potential methods of improving the cultural sensitivity, responsiveness and approachability of people, systems, and organisations involved in Aboriginal cancer control.

Treatment

Aboriginal cancer patients are less likely to complete curative treatment; the precise reason for this is unknown, although it is likely to relate, at least in part, to transportation issues. Cancer treatment pathways need to be measured in order to gauge improvement and variation.

Recommendation 25: To address treatment incompleteness investigation into the following areas is necessary: the manner in which decisions about treatment options are made, and who makes them; whether the problem of incomplete treatment is more to do with starting treatment, or with completing it; and the nature of the barriers preventing Aboriginal people from completing treatment (as well as ways of reducing their impact).

Aboriginal people have competing social, cultural and family demands that may impact on cancer treatment. A useful way to address treatment incompleteness may be to determine how successful treatment should be defined for Aboriginal people, what Aboriginal people want from cancer treatment, and how the balance between quality of life and survival differs between Aboriginal people and other Australians. In such an approach, AIHW's measure of community functioning (ABS & AIHW, 2008) may contribute or efforts may be directed at developing and validating new indices of health outcomes. Appropriate models that engage the Aboriginal community and define health and wellbeing according to community priorities need to be developed with a view to implementation at a national level. Aboriginal participation and ownership in service delivery is an important objective, as is the improvement of methods of communication concerning cancer, its causes and treatment.

Recommendation 26: Develop treatment models that engage the Aboriginal community and define health and wellbeing according to community priorities. Objectives will include Aboriginal participation and ownership in service delivery, as well improving methods of communication concerning cancer, its causes and treatment.

Survivorship

Very little information about rehabilitation services for Aboriginal cancer patients is available. Research needs to be conducted into Aboriginal patients' access to and benefit from rehabilitation services, barriers that need to be addressed in order to facilitate the return of Aboriginal people to community and home life, and which approaches will best assist in ensuring follow-up is maintained.

Recommendation 27: Research needs to be conducted into Aboriginal peoples access to and benefit from rehabilitation services and which approaches will best assist in ensuring follow-up is maintained.

Palliative care

Awareness of palliative care is low among Aboriginal cancer patients. Research should be conducted into methods of improving Aboriginal awareness of palliative care, Aboriginal perceptions and knowledge about palliative care and what ought to constitute effective palliative care in the context of Aboriginal communities.

There is a common fatalism about the outcome of cancer. Although stories about Aboriginal cancer survivors are currently being promoted in an effort to address this issue, further research should be pursued investigating ways in which Aboriginal cancer survivors can assist in changing this perception, and how peer-led programs can support Aboriginal cancer patients and families.

Mainstream hospital services often fail to recognise the importance in Aboriginal culture of dying within the community and the needs of the extended family. A better understanding is needed of how family involvement can be incorporated into mainstream services for Aboriginal people, how end of life decisions are made by Aboriginal people, and how effectively pain is managed. This will be best achieved through the involvement of Aboriginal people in the development of health services.

In remote areas, the following barriers to palliative care have been identified: a lack of funding, inadequate availability of other resources, and remoteness. It is not yet clear how these barriers can best be overcome. Improved funding and training should be directed at the unique needs of remote residents. Research should also be carried out into how palliative care services can be best provided to remote communities, and how mainstream palliative care services can be appropriately adapted for Aboriginal patients.

Recommendation 28: Research should be conducted into methods of: improving Aboriginal awareness, perception and understanding of palliative care; involving Aboriginal people and their families in palliative care decisions; providing effective palliative care in the context of Aboriginal communities.

Recommendation 29: Research should be carried out into what ought to constitute effective palliative care in the context of Aboriginal communities. This should include investigation into the ways in which end of life decisions are made by Aboriginal people, how effectively pain is managed, and methods of incorporating family involvement into mainstream palliative care services for Aboriginal people.

Recommendation 30: Funding and training should be directed at the palliative care needs of remote residents, as well as research addressing optimal methods of palliative care service provision in remote communities.

Other Chronic Disease Programs

The current work focussed on the available literature and verbal reports of programs of relevance to cancer control. It was beyond the scope of the current report to address research and program activities with Aboriginal communities focused on other chronic diseases (e.g., diabetes, cardiovascular disease, asthma etc.). It is likely, however, that important lessons could be learnt from an exploration of successful models in other chronic disease areas, and that partnerships with health services and NGOs working with different disease groups may leverage better outcomes.

It is important that investigation be carried out into work involving Aboriginal people in other chronic disease areas (for example, cardiovascular diseases, diabetes, and chronic respiratory diseases). Where programs have been successful, factors behind this success should be analysed in detail, and, if appropriate, similar models should be tested with Aboriginal groups in the context of cancer control. The possibility of partnering with NGOs and health services working within other chronic disease groups should also be considered.

Recommendation 31: Research should be carried out into models that have been successful with Aboriginal people in other areas of chronic disease, with consideration for the possibility of trialling similar models in the context of cancer control for Aboriginal Australians.

CONCLUSION

In summary, a proper understanding of what constitutes best practice for Aboriginal people within the context of cancer control has yet to be developed. Optimal methods of improving cancer services for Aboriginal people are not fully understood at present. There is currently a lack of evidence-based research addressing the responsiveness of cancer services to the needs of Aboriginal people. Despite data deficiencies, there are conclusions that can be drawn from the studies on cancer control in Aboriginal communities conducted in Australia. These studies identify higher population-based cancer mortality and lower survival rates compared to non-Aboriginal Australians. Aboriginal people experience lower rates of cancers of the breast, prostate, colon and rectum, as well as melanoma and lymphoma. The findings also indicate a higher prevalence of high fatality cancers, more advanced stage of diagnosis, and greater co-morbid illness, coupled with poorer access to care and less comprehensive treatment. Aboriginal people display higher levels of smoking, hepatitis B carriage, excessive alcohol consumption, poor diet, and lower participation in screening programs.

This review focussed upon assessing existing evidence on cancer control in Aboriginal people in order to recommend solutions to barriers and gaps in evidence. The aim of the gap analysis performed as part of this review was to propose solutions to improve Aboriginal cancer control either through endorsement of particular evidence-based activities and/or through the identification of research opportunities.

Recommendations can be summarised into four main areas—

Data Infrastructure: Without data of good quality health issues cannot be defined, appropriate service responses implemented and progress assessed. In particular, jurisdictional data in cancer registries and administrative data on cancers in Aboriginal people need to be collected in a consistent manner with adequate descriptors of Aboriginal status for meaningful geographical and secular comparisons.

Programs: Although the evidence is clear that disparities in cancer outcome occur in Aboriginal people, further work is required to increase the evidence-base underpinning efforts to improve cancer control in Aboriginal communities. Cancer Australia may consider developing funding models to support programs across the cancer pathway, although there should be a requirement that the programs be evaluated using systematic methodology and long-term follow up of outcomes.

Prevention: Research is urgently needed to inform primary prevention initiatives that address risky lifestyle choices in Aboriginal communities. Adequate engagement and acknowledge of the values, beliefs and preferences of Aboriginal people is required. Caution is required against over-generalisation and a need to explore the subtle differences in views about cancer control within Aboriginal communities, between communities, and between urban, rural and remote locations.

Service Delivery: Given the failure of current service delivery models to reduce disparities in cancer outcomes for Aboriginal people, it may be necessary to consider a new paradigm for the delivery of services. Research should be carried out investigating which models work best in different contexts, how services can move towards these models, and methods of measuring improvement.

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