



National Indigenous Cancer Network (NICaN) Breast Cancer Research Roundtable

2014

Report

NICaN Partners



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For the purposes of this document, 'Indigenous' respectfully refers to Australia's Aboriginal and Torres Strait Islander peoples.

Summary

This report provides an overview of the National Indigenous Breast Cancer Research Roundtable, held at the Lowitja Institute, Melbourne Australia on Wednesday, 27 August 2014.

Breast cancer is the most commonly occurring cancer amongst Aboriginal and Torres Strait Islander women, respectfully referred to as Indigenous in this report. Although Indigenous women are less likely to get breast cancer than other non-Indigenous women, they are more likely to die from breast cancer. The reasons for this are multifactorial and may include: late cancer stage at diagnosis, when the disease is more difficult to treat; lack of access to appropriate cancer services; and poorer general health.

Overview and background of the Roundtable

The Roundtable was an initiative of the National Indigenous Cancer Network (NICaN) and the Menzies School of Health Research, with funding provided by the National Breast Cancer Foundation.

Research roundtables are an important part of ensuring Indigenous community organisations, government, and other stakeholders come together to play an integral part of setting the research agenda in cancer and Indigenous communities. The National Indigenous Breast Cancer Research Roundtable is the third research roundtable, and the second that NICaN has hosted, to identify research gaps, priorities and opportunities for collaboration in the area of cancer and Indigenous Australians. This Roundtable brought together a wide range of key stakeholders to provide input in identifying and prioritising breast cancer research among Indigenous Australians.

Participants

The Roundtable was attended by over 45 people from a wide range of health sectors, cancer care organisations and services, and research groups involved with cancer in Indigenous people.

Overview of the day

The day was divided into four sections: (1) Welcome to Country and introductions; (2) presentations covering cancer epidemiology, cancer treatment, breast screening, familial cancer services and genetics testing, patient and doctor interaction, and the supportive care needs of Indigenous patients with breast cancer; (3) small group discussions of key issues; (4) identification of key research priorities.

Research Themes and Outcomes

Two primary themes were discussed at the Roundtable:

- (1) Early detection, risk management, and screening; and
- (2) Treatment, care, and survivorship.

The group also identified a number of underpinning themes that were to be discussed in their group discussions, including; empowerment, community and consumer engagement and

involvement, culture, holism and complexity, structure and governance, and principles of collecting and managing data.

Three key priorities relating to early detection, risk management, and screening for breast cancer amongst Indigenous women and communities were identified:

- Review and evaluation of existing research, programs, and services;
- Breast awareness and health literacy; and
- Screening.

Two key priorities relating to treatment and supportive care for Indigenous women with breast cancer were identified:

- Barriers to accessing and completing treatment; and
- Culturally appropriate service delivery.

Participants who responded to a post-roundtable survey listed early detection and screening, education and disease awareness, and support services for Indigenous women as key priorities for further research. Representatives from a number of organisations professed a willingness to collaborate in future endeavours, including Cancer Australia, Menzies School of Health Research, the University of South Australia, The University of Melbourne, School of Public Health University of Sydney, the national kConFab research consortium, Peter MacCallum Cancer Centre.

Conclusions

The National Indigenous Breast Cancer Research Roundtable provided a forum to discuss, develop and prioritise a research agenda with the aim of improving outcomes for Indigenous people with breast cancer. Breast cancer survivors and advocates, cancer researchers, government representatives and health service personnel considered a broad range of topics, the culmination of which was a list of research priorities. The overarching themes were (1) the need to enhance early detection, risk management, and screening and (2) to improve cancer treatment uptake and care, and survivorship for Indigenous people. A number of participants agreed to collaborate to further these research agendas.



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1. Introduction

Breast cancer is the most common cancer experienced by Indigenous women. While the rate of breast cancer is lower in Indigenous women than non-Indigenous women (82 and 104 per 100,000 women respectively), Indigenous women are 1.3 times more likely to die from breast cancer (five year mortality rates of 28% and 21% respectively) (AIHW 2013). It has been suggested that these disparities may be related to lower participation in screening programs, lack of access to appropriate treatment and support services, and reduced likelihood of completing appropriate treatment.

Indigenous women are more likely to be diagnosed with breast cancer at a younger age than non-Indigenous women, and to have more advanced breast cancer and larger tumours when they are diagnosed. Indigenous women are also more likely to have a mastectomy rather than tumour removal (Supramaniam 2014). Further information from current research on breast cancer and Indigenous people was presented at the Roundtable and is summarised in Section 3.



The Roundtable was an initiative of National Indigenous Cancer Network (NICaN) and the Menzies School of Health Research, with funding provided by the National Breast Cancer Foundation. It brought together researchers, service providers, health professionals and breast cancer survivors to develop research priorities for breast cancer among Aboriginal and Torres Strait Islander women. More information about the outcomes of the day is provided in this report.

1.1 Background of the Roundtable, NICaN, and DISCOVER-TT

Roundtables on Cancer in Indigenous Australians have been held in Brisbane in 2010 (Garvey, 2011) and 2013 (Menzies School of Health Research, 2013). Both were convened by Gail Garvey, Division Leader of Epidemiology and Health Services at the Menzies School of Health Research. A tangible outcome of the first Roundtable in 2010 was the successful application for funding to create a national, collaborative, Indigenous-led research effort in this area. The Centre for Research (CRE) Excellence in *Discovering Indigenous Strategies to Improve Cancer Outcomes via Engagement, Research Translation, and Training* (DISCOVER-TT) was then officially launched as part of the 2013 Roundtable.

On the day following the 2013 Roundtable, there were a number of related face-to-face meetings, including the inaugural meeting of the DISCOVER-TT Advisory Board, a meeting of the DISCOVER-TT Management Team (consisting primarily of the CRE's 10 chief

investigators and 20 associate investigators) and planning meetings for those involved in each of the eight projects to be undertaken in the first few years of DISCOVER-TT.

NICaN was established to focus on addressing critical cancer research and service delivery issues relevant to Australia's Indigenous peoples. NICaN is a collaboration between Menzies School of Health Research, the Lowitja Institute, the Australian Indigenous Health/InfoNet and the Cancer Council Australia.¹ This is an important agenda to pursue because while cancer causes more deaths amongst Indigenous peoples than diabetes and kidney disease combined (ABS, 2014), it has received less attention and Indigenous Australians generally experience poorer outcomes from cancer than non-Indigenous Australians (AIHW, 2013). One vehicle for this work is DISCOVER-TT which aims to address disparities in the treatment and survival of Australian Indigenous people with cancer.²

Previous Roundtables on cancer and Indigenous communities identified some clear messages in relation to research in this area, which are being actively pursued by NICaN partners, DISCOVER-TT, and other stakeholders. These include the importance of: a nationally integrated approach where proposed research builds systematically on successive research initiatives; Indigenous leadership; considering all stages of the consumer/patient journey; a systems approach to improving the quality of care; a coordinated, collaborative and strategic direction for the research; and ensuring there are processes and structures to support translation of research into practice. Priority research topics associated with data collection and management, service delivery and models of care, workforce development and education, communication, consumer advocacy and support, and prevention were also identified.³

This work formed the basis for the NICaN Breast Cancer Research Roundtable, the aim of which was to bring together cancer survivors, researchers, service providers, advocacy groups, and community representatives (Appendix 1) to identify a national research agenda specific to breast cancer and Indigenous women.

¹ For further information about NICaN see <http://www.nican.org.au/>

² For further information about DISCOVER-TT CRE see http://www.menzies.edu.au/page/Research/Centres_initiatives_and_projects/Centre_for_Research_Excellence_Cancer/.

³ For a report on the 2013 Roundtable see http://www.nican.org.au/NICaN_Roundtable2013/uploads/2013-11-22_roundtable_priorities_report_FINAL.pdf

The Roundtable built on a review of Aboriginal and Torres Strait Islander Cancer Control research also published in 2010 – see http://canceraustralia.gov.au/sites/default/files/publications/atsi_cancer_control_research_report1_504af02522aa_1.pdf

2. Outline of the day

Romilie Mokak, CEO of the Lowitja Institute, greeted the Roundtable participants and welcomed them to the Lowitja Institute. Aunty Dianne Kerr, a Wurundjeri Elder who identifies with the Ganun Willam Balak clan, then performed a moving welcome to country ceremony and spoke about the impact of breast cancer on Indigenous women and their families. The Honourable Dame Quentin Bryce made the opening address. She spoke of her familiarity with the challenges of delivering health services



in far north Queensland and the exciting work being done by young doctors and allied health professionals, and made special mention of James Cook University, Townsville. She noted that we are all connected with breast cancer and reflecting on improvements, there is much to celebrate; this arena has had the most successful public lobby but there are continuing challenges and it is a top priority to discuss these issues at this Roundtable.

Opening addresses were followed by presentations from David Roder, Suzanne Moore, and Raj Supramaniam, describing current understanding of the burden of breast cancer for Indigenous people and the breast cancer care that Indigenous women receive. Rachael Andersen from BreastScreen Victoria spoke about screening services Australia-wide, and Leanne Pilkington an Aboriginal Program Officer from BreastScreen Western Australia



spoke about breast screening services in that state. Heather Thorne from kConFab spoke about work in familial breast cancer and genetics and opportunities that are available in this area. Breast cancer survivor, Annette Lawrence and her treating physician, Roshie Kamyab, spoke about their shared experience when Annette was diagnosed with breast cancer. Gail Garvey spoke about supportive care needs for Indigenous people with breast cancer and about the need to

develop and prioritise a collaborative research agenda to address disparities in outcomes for Indigenous people.

Summaries of these presentations can be found in the following section and a copy of the agenda can be found in Appendix 2.

3. Presentations

3.1 An overview of breast cancer research in Aboriginal and Torres Strait Islander Women in Australia – David Roder and Suzanne Moore

The first presentation was given by David Roder and Suzanne Moore on 'An overview of breast cancer research in Aboriginal and Torres Strait Islander Women in Australia'. Suzanne gave a summary of the information known to date about breast cancer among Indigenous women (some of which is summarised in a handout seen in Appendix 3), including;

- Demographics and cancer information;
- Risk factors;
- Incidence, survival and mortality;
- Treatment;
- Service use and screening behaviour; and
- Other information such as the role of racism, culturally appropriate information and services, and other related health issues.

David expanded on this by giving some more specific details. David pointed out that Indigenous women have a 21% lower chance of being diagnosed with breast cancer (lower in most age groups except one) but a higher mortality rate. David presented emerging results from a cohort study in South Australia (participant numbers are still small) which reported poorer survival in Indigenous women from breast cancer across all age groups, as well as poorer survival among Indigenous women who live in rural/remote areas, compared to non-Indigenous women living in equally rural or remote locations.

Other data showed, after taking into account geographical location and age, that Indigenous women with breast cancer are at a twofold risk of case fatality compared with corresponding non-Indigenous women. David also used other data to show that after adjusting for socio-economic status, Indigenous women participated less frequently in breast screening, had larger breast cancers and were more likely to have mastectomy than local excision. He presented the results of a matched cohort study in Queensland which reported similar breast cancer histology between Indigenous and non-Indigenous women.

David then spoke about a data linkage project underway in South Australia, in partnership with the Aboriginal Health Council, the SA Government, the SA Health and Medical Research Institute and Cancer Council SA. The project is led by an Indigenous researcher and has a Indigenous-majority steering committee. It focuses on strengthening cancer registry data and linking with administrative data, to assess stage, stage-specific survivals and patterns of care and screening participation. Importantly, qualitative data is being collected from Aboriginal and Torres Strait Islander patients about their experiences in the health system. Finally, David concluded by indicating his personal interests in seeing this

type of model considered throughout Australia, where statistics are combined with cancer stories to get a more comprehensive picture.

3.2 Breast cancer treatment for NSW Aboriginal Women – Rajah Supramaniam

Rajah Supramaniam gave the second presentation 'Breast cancer treatment for NSW Aboriginal Women'. Raj presented the data from a population based study they had undertaken in NSW linking registry data with hospital surgical data to look at treatment differences between Aboriginal and non-Aboriginal women. The NSW experience reflected findings from across Australia, namely, that Aboriginal women, compared to non-Aboriginal women, were diagnosed at an earlier age, were more likely to have advanced disease and had higher mortality rates and lower survival rates.

Raj explained that in their study they found that Aboriginal women had 40% lower odds of getting surgery within 12 months of diagnosis compared to non-Aboriginal women and while



differences in spread of disease, age, geographical location and socio-economic status could partially explain lower survival for Aboriginal women, the main predictors of lower survival were comorbidities and surgical treatment. Raj then spoke about the Cancer Council NSW Patterns of Care Study where they undertook a detailed clinical audit of 23 hospitals and three clinical cancer registries to discover what treatments Aboriginal women were having. They found that radiotherapy was less common the more remotely someone lived, while surgery was slightly more common among those living more remotely;

chemotherapy and hormone therapy rates were similar irrespective of how remote the woman's place of residence. Raj concluded by explaining that Aboriginal women who attend NSW hospitals were receiving reasonable levels of medical care.

3.3 National Breast Cancer Screening Program – Rachael Andersen

Rachael Andersen presented on the 'National Breast Cancer Screening Program'. Rachael gave some background about the program, how it works and the target group it is aimed at. She explained that the program is delivered differently in each state and territory with some states having only permanent sites and some having mobile vans, as well as some services being delivered by public services and others being privately run. The recruitment strategies used in each state and territory are also different and may impact on screening rates.

Rachael then shared some screening statistics and explained that while screening rates are over 50% for non-Indigenous women; Indigenous women still have much lower rates (36% compared to 54%). Some of the barriers and challenges to higher participation in screening by Indigenous women include;

- Perceived lack of cultural safety in mainstream services and related medical distrust;
- Use of one-size-fits-all service system models;
- Stress and social isolation;
- Socioeconomic disadvantage;
- Multiple and complex morbidities and other health and life priorities; and
- The existence of shame feelings connected to breast cancer.

Rachael concluded by discussing equity of access and the importance of developing partnerships with community and drawing from leadership from within community as a way of increasing uptake in breast cancer screening.



3.4 Barriers to breast cancer screening and strategies used by BSWA to overcome them – Leanne Pilkington

The fourth presentation 'Barriers to breast cancer screening and strategies used by BreastScreen Western Australia to overcome them' was given by Leanne Pilkington and complemented the previous presentation about breast cancer screening. Leanne began by discussing what impacts on breast cancer screening uptake, such as: culture, language, spiritual beliefs, individual diversity, and perceptions of racism/past experience. Leanne discussed how some women don't want to do a mammogram because they don't see the point and even if they get breast



cancer they won't have treatment. Some women also see cancer as payback for doing something wrong and this isn't just something thought by women who follow a more traditional lifestyle. She also stressed that even if services are not racist it's important to think about the perception of the client and how they see the service.

Leanne then spoke about some of the challenges of screening Indigenous women. High staff turnover among health workers was a big issue. Clients become comfortable with the health worker, who is able to establish good relationships and increase participation in screening but if that person leaves there is a lack of continuity. It is important to recruit passionate open-minded staff that are willing to look at different ways of working with women.

Lack of understanding was another issue. Some women thought mammograms cause cancer and there needs to be an emphasis that it is for well women and prevention. It is also important to educate people that there is a need for continual screening and it is not just something you do once. There are significant issues around access and travel for screening. At certain times of the year people may not be able to travel and for remote communities the physical distance between towns makes it hard to access services.

Leanne finished by saying that the BreastScreen WA service is performing slightly better than those in other states and this may be due to strategies such as:

- Employing Indigenous program officers and establishing an Indigenous Women's Reference group;
- Genuine feedback from women in community on all aspects of service;
- Using flipcharts and visiting communities to explain what the service is;
- Providing transport and accommodation assistance in remote regions;
- Working with other women's health services;
- Encouraging survivors to be visible and asking them to share their stories; and
- Improving acceptability of services and removing racism (which may be incidental and not immediately obvious).

3.5 Family history of breast cancer – Heather Thorne

The fifth presentation was given by Heather Thorne on 'Family history of breast cancer'. Heather began by explaining that 10% of families are at "high risk" and have a genetic basis for developing breast cancer and that kConFab had been established as a multidisciplinary



research group to collect and store biological samples to facilitate national research into the genetic aspects of breast and ovarian cancer. Blood and tissue samples are sent to the Peter MacCallum Cancer Centre where they are processed and analysed, and life style and clinical treatment data is collected. The group has four entry criteria for families to be added to be part of their service; high risk non BRCA 1/2 gene

carriers, BRCA 1/2 gene carriers, carriers of other known genes, fresh tumour collection. Any researchers with ethically-approved projects can apply for access to this data to use in genetic studies.

Heather explained that in addition to benefits for research there are some direct benefits for people taking part in a genetic clinical service, including: a personal risk assessment for the

gene carriers and non-carriers, and the ability to access gene targeted clinical trials for cancer treatment and cancer prevention. She also shared some data around the number of families and participants accessing the service. Seventy-five participants from 42 families have indicated having an ethnic background which includes Aboriginal/Torres Strait Islander/Maori ethnicity.

3.6 Supportive care needs amongst Indigenous Australians with cancer: comparing breast cancer and all other cancer preliminary findings – Gail Garvey



Gail Garvey presented some preliminary data from a study conducted in Queensland about the 'Supportive care needs amongst Indigenous Australians with cancer: comparing breast cancer and all other cancers'. Gail began by explaining the definition of supportive care and its aim. She also shared the tiered model of supportive care which looks at the level of needs and the types of services that may be needed to meet the

unmet needs of cancer patients. Indigenous people with cancer are more likely to have complex needs, and as a result are more likely to report higher unmet supportive care needs. She then described a new supportive care needs tool that has been developed specifically for Indigenous cancer patients, that is culturally appropriate and is a valid and reliable measure of unmet needs for Indigenous cancer survivors. This tool was used to collect information about the support needs of Indigenous cancer survivors in Queensland.

Gail then spoke about her preliminary results and the differences in results between Indigenous women with breast cancer compared to all other cancers. Women with breast cancer were more likely than other cancer patients to have completed secondary and post-secondary education, be treated as outpatients, be employed, and reported having mainly contacts with other Indigenous Australians. Indigenous women diagnosed with breast cancer were less likely to need help with physical pain, feeling unwell, help around the home, feeling anxious and having concerns about the worries of those close to them. However, they were more likely to be positive in their spirit (staying positive) but also more likely to experience distress related to their cancer.

Gail concluded by saying there were limitations to this preliminary data as the all cancers group contained both male and female patients verses only female patients in the breast cancer group. It is unknown why women with breast cancer report higher distress or why

they feel more positive in their spirit and have fewer concerns about the worries of those close to them. There is a need to conduct further analysis and look at a larger sample size.

3.7 Survivorship Q&A – Roshi Kamyab and Annette Lawrence

Roshi Kamyab and Annette Lawrence gave a 'Survivorship Q&A' by sharing their experiences with breast cancer. Annette is an Aboriginal woman who was diagnosed with breast cancer in 2010 and Roshi was the surgeon who treated her. Roshi and Annette began by recounting how Annette was diagnosed with breast cancer (as she was not yet at the age for screening). They then spoke about how it felt to be diagnosed with breast cancer, as well as what type of treatment Annette received and how she is coping following the treatment. Roshi also asked Annette about how her family coped with the diagnosis and what advice she has for other Aboriginal women. The session concluded with questions and statements from the audience about the importance of engaging Indigenous cancer survivors and making them feel supported.



3.8 Summary of relevant research priorities in breast cancer and Aboriginal and Torres Strait Islander people – Gail Garvey

Gail Garvey concluded the presentations by giving a 'Summary of relevant research priorities in breast cancer and Aboriginal and Torres Strait Islander people'. Gail began by saying that much of the research so far has focused on the entire picture of cancer but we are now at a time to begin to focus on specific cancers, such as breast cancer.

In the 2010 Aboriginal and Torres Strait Islander Cancer Control Research Project Report produced by Cancer Council South Australia (funded by Cancer Australia) there were 31 recommendations, of which one related specifically to breast cancer. However, there were many other more general recommendations which are still relevant and can be tailored to breast cancer research, including; the importance of data linkage, the need for culturally appropriate services, language and communication, the role of palliative care and the importance of evaluating and enhancing communication and interaction with health services. Gail concluded by sharing the NBCF National Action Plan for Breast Cancer Research priorities which are specific to Indigenous women and men, the research priorities from the National Indigenous Cancer Network Roundtable, and the Cancer Australia Research priorities from the Priority-driven Collaborative Cancer Research Scheme.

Presentation slides and short videos of each presentation are available online at:

http://www.nican.org.au/NICaN_Roundtable2014/presentations.htm



4. Group Discussions

Three discussion streams were identified prior to the Roundtable: (1) prevention and screening; (2) treatment and care; and (3) survivorship. At the Roundtable it was decided that 'prevention' should be replaced with 'early detection and risk management' as there were no really clear strategies for primary prevention in breast cancer. Survivorship was combined with treatment and care. Therefore the two streams discussed were:

- (1) Early detection, risk management, and screening; and
- (2) Treatment, care, and survivorship.

Participants were asked to join a group that was of most interest to them. Breast cancer survivors were invited to join each group to ensure that first-hand experiences were incorporated into the discussions. Discussions in each of these streams centred around:

- The most salient issues in this area and what gaps exist in the research; and
- Key priorities for moving forward in each area.

4.1 Stream 1 – Early detection, risk management, and screening

4.1.1. Issues and gaps in research

Four key issues and gaps in research relating to early detection, risk management, and screening for breast cancer amongst Indigenous people and communities were raised:

- Breast awareness and health literacy;
- Screening;

- Communication; and
- Knowledge translation and ownership of data.

Below are specific examples of issues and gaps in research that were discussed surrounding early detection, risk management, and screening.

Breast awareness and health literacy

- Limited knowledge and awareness about breast cancer and about the importance of early detection, risk management and screening. It was acknowledged that people may not be able to recognise symptoms, may not have anyone in their family or community to talk with about breast cancer, and may not know that early detection improves survival. This also related to a range of issues with health literacy.

Screening

- Low participation in screening, including both individual and community-level barriers to screening.
 - Individual-level barriers include: people being fearful of finding out they have breast cancer or not wanting to know if they do have it; stigma associated with talking about breast cancer; fear of discrimination and of being treated poorly; family member attitudes to seeking services; other life priorities; and not prioritising one's own health.
 - Community-level barriers include: service related issues such as limited access to screening and follow up due to a range of factors such as the service (even a mobile one) being too far away; lack of Indigenous staff; discrimination; and that the language used might be ineffective for communicating with Indigenous people.
- Not enough knowledge about enablers to effective early detection, risk management, and screening. We have an understanding of several barriers but we don't yet know about enablers.
- Difficulty accessing screening and health services. This may be due to factors such as remoteness, and lack of Indigenous staff in these programs and services.
- Need for family and community-based models to promote breast cancer awareness and screening, rather than only targeting individuals. Designing appropriate models for rural/remote and urban areas.



Communication

- Lack of integration between screening and health check services.
- Absence of a shared language between service providers and Indigenous communities about breast cancer. This includes all aspects of early detection, risk management, and screening.
- Lack of feedback and evaluation on services and programs. This includes both what does and does not work in these services and programs.
- Limited sharing of information between States and Territories. This results in hindering of knowledge about strategies that do and do not work.

Knowledge translation and ownership of data

- Limited knowledge transfer back to communities. Communities may not be directly benefiting from knowledge and research.
- Indigenous peoples should be custodians of their data.

4.1.2. Key priorities

Three key priorities relating to early detection, risk management, and screening for breast cancer amongst Indigenous people and communities were identified:

- Review and evaluate existing research, programs, and services;
- Breast awareness and health literacy; and
- Screening.

Below are specific examples that were discussed under each of the key priorities within early detection, risk management, and screening.

Review and evaluate existing research, programs, and services

- Review and evaluate current services and current knowledge. This would include identifying what works well, and why it works. It is also imperative to gain an understanding of how to adapt initiatives to transfer across communities and regions.

Breast awareness and health literacy

- Develop effective health literacy and communication strategies specific to Indigenous people.
- Develop new ways to raise awareness about breast cancer and the benefits of breast cancer screening. This could include an involvement of consumers and communities.
- Evaluating strategies to promote breast awareness, identifying those that are effective, and sharing this knowledge.
- Understanding stigma and shame regarding cancer and screening for cancer. This would also include developing ways to address stigma and shame, to improve early detection, risk management, and screening.
- Understanding individual, family, and community-level factors that influence health seeking behaviours.

- Improving earlier diagnoses by exploring ways to encourage medical specialists into remote areas.

Screening

- Develop a better understanding of the issues that impact on participation in screening and how to address these (both enablers and barriers to screening). This work could include the perspectives of community members, service providers and survivors. Further steps would include translating this research into interventions to improve screening rates.
- Develop and test alternative service delivery models, with attention to how screening services may differ for rural/remote and urban areas. This might include:
 - A family and community-based approach to screening;
 - Enabling Indigenous community leaders to promote screening;
 - Models that enable flexibility so that people's needs can be better met; and
 - Integration of breast screening with other screening programs.

4.2 Stream 2 – Treatment and supportive care

4.2.1. Issues and gaps in research

Two key issues and gaps in research relating to treatment and supportive care for Indigenous women with breast cancer were raised:

- Barriers to accessing and completing treatment; and
- Culturally appropriate service delivery.

Below are specific examples that were discussed under each of the issues and gaps in research within treatment and supportive care.

Barriers to accessing and completing treatment

- Limited knowledge about the barriers that are preventing women from accessing and finishing treatment and designing interventions to overcome these barriers. This can include economic, geographic, cultural, supportive needs, financial, and health literacy factors.
- A range of issues regarding follow-up treatment (e.g., adjuvant treatment, hormone therapy) have yet to be explored. This includes a lack of understanding of what treatments are being offered and why Indigenous women do not complete long-term treatment plans.
- There is limited participation of Indigenous women in clinical trials and access to these trials needs to be improved.
- A lack of understanding of the impact of complex health needs on treatment for breast cancer, including high rates of comorbidities.

Culturally appropriate service delivery

- A lack of relevant and appropriate information regarding diagnosis and treatment.
- Culturally specific needs of Indigenous women are not being met during their treatment for breast cancer.
- A lack of information on patient's needs and how to provide supportive care to help women cope.
- A shortage of Indigenous health workers.

4.2.2. Key priorities

Consistent with the gaps in the research, two key priorities relating to treatment and supportive care for Indigenous women with breast cancer were identified:

- Barriers to accessing and completing treatment; and
- Culturally appropriate service delivery.

Below are specific examples that were discussed under each of the key priorities within treatment and supportive care.

Barriers to accessing and completing treatment

- Gain an understanding of current practice. This includes a number of aspects of treatment and supportive care, including:
 - Comparison of cancer treatment and outcomes between Indigenous and non-Indigenous women, including stage at diagnosis, treatment centre, treatment offered/provided, adjuvant treatment, and follow up.
 - Economic, geographic, cultural, and health literacy factors preventing women from accessing treatment.
 - Qualitative assessment to gain an in-depth understanding of treatment experiences, including why some Indigenous women do and do not access treatment.
- Understanding the impact of complex health needs, including high rates of comorbidities.



Culturally appropriate service delivery

- Developing models of care for both treatment and support services. This includes factors such as patient navigation, increasing numbers of Indigenous health workers, and flexibility of service. This also includes overcoming cultural barriers and factors such as fear that may prevent Indigenous women accessing treatment and support services.

- Understanding psychosocial needs of Indigenous women diagnosed with breast cancer and their families, and the best ways to provide supportive care and help people cope after cancer. This includes how to provide support when people are in their own communities and if they are displaced during treatment.
- Understanding, acknowledging, and meeting culturally specific needs of Indigenous women during their treatment for breast cancer. This can include language, family, social, and spiritual needs.

4.3 Underpinning themes

Several underpinning themes were also identified that were relevant to both topic areas of 1) early detection, risk management, and screening, and 2) treatment and supportive care. These themes were discussed as integral components of any future work or research with Indigenous people and communities. These themes included:

- Empowerment of Indigenous women and men throughout the whole breast cancer journey.
- Community and consumer engagement and involvement in all work (including research) to improve care and outcomes so that their perspective is central to this work. While doing so, it is important to take into account that:
 - Indigenous peoples are diverse and we cannot assume programs and services can be generalised between communities. It is important that communities are consulted about what works for them;
 - Developing relationships between service providers, researchers and communities can be an extensive process;
 - It is important to give back to communities and invest in continuing relationships over time. For example, be creative about doing projects which may not fit into research grants if they are an important need for the community. This might include supporting awareness activities and community events;
 - Knowledge translation of results into models of care and support to improve health outcomes.
- Culture – attention to how Indigenous cultures can inform new ways of working to improve care and support across the continuum from early detection to long-term survivorship. This includes understanding the importance and role of family and working with more than just the individual patient. Conversely, attention is needed on how prevailing cultural practices within care and support services can impact on the experience (and outcomes) of individuals.



- Holism and complexity – We need to consider how health care can be provided in ways that take account of whole people, including capacity to work in ways that address the complexity of people's health conditions, such as the presence of co-morbidities. Further, we need to address a fragmented service system that does not provide continuity of care over early detection, diagnosis, treatment, and supportive care.
- Structure and governance of research and capacity building of researchers and communities to work together, share knowledge, and build understanding.
- Principles of collecting and managing data:
 - It is important to ensure that processes for data collection are ethical and that communities are engaged throughout the entire process from research question design to research translation. Indigenous reference groups need to be incorporated into the research process and are integral in research dissemination.
 - Accurate data collection from cancer care and prevention services, ensuring that data collected is appropriate for both clinical and research use.
 - Many researchers already have data relevant to breast cancer and Indigenous people and communities. A priority should be to work collaboratively to bring the data together.
 - Researchers need to look at ways to share data with communities who have participated in research. Information needs to be easy to understand, appropriate and respectful.
 - Ownership of data and information should be vested with Indigenous communities and individuals, and Indigenous people should benefit from owning and sharing this information.

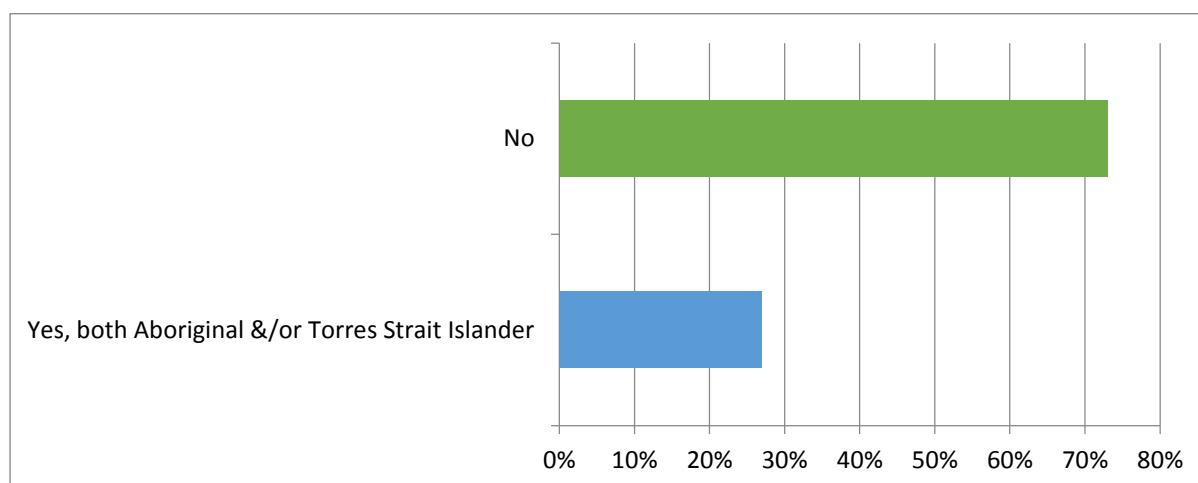
5 Feedback and evaluation

Due to time limitations it was not possible to prioritise the research topics at the Roundtable. Instead, participants were thanked for their engagement and input, and it was agreed that the afternoon's session was the start of an important conversation, rather than the completion of a finite task. Participants were sent a survey (through Survey Monkey) with the abovementioned research priorities (sections 4.1.2. and 4.2.2.) and asked to indicate their interest in the areas that they would considered pursuing in collaborative research effort with others. The results of the survey completed by roundtable attendees, along with the results of a pre and post roundtable evaluation survey are presented here.

5.1 Pre-roundtable survey

One week prior to the Roundtable, participants were asked to complete an online survey containing questions about their expectations for the day and what they saw as research priorities.

Twenty seven participants completed the pre-roundtable survey (60%⁴ response rate). Of these, most respondents were not Indigenous and one person did not complete the question (graph 1)⁵. Twelve (44%) participants were researchers or academics, eight (30%) were health professionals, three (11%) were Aboriginal and Torres Strait Islander community members, two (7%) were cancer survivors or advocates, two (7%) were students and seven (26%) brought other perspectives including those of funder, government officer, policy maker, manager and clinician.



Graph 1: Pre-survey: Are you of Aboriginal and/or Torres Strait Islander origin?

Expectations for the Roundtable

Twenty four respondents described their expectations for the Roundtable. These included:

1. To be guided by Indigenous leadership.
2. To share knowledge, experience and understanding of: 1) issues associated with breast cancer for Indigenous women and populations; 2) initiatives currently occurring across Australia; 3) evidence based models for health promotion, treatment and screening; and 4) evidence gaps and research priorities for breast cancer in Indigenous women.
3. Discussion and identification of:
 - Gaps and issues in breast cancer service delivery for Indigenous populations (or women) in Australia across the continuum from risk modification and screening to treatment and support.
 - Priority issues to be addressed through research, including:
 - Improved or more systematic data collection;

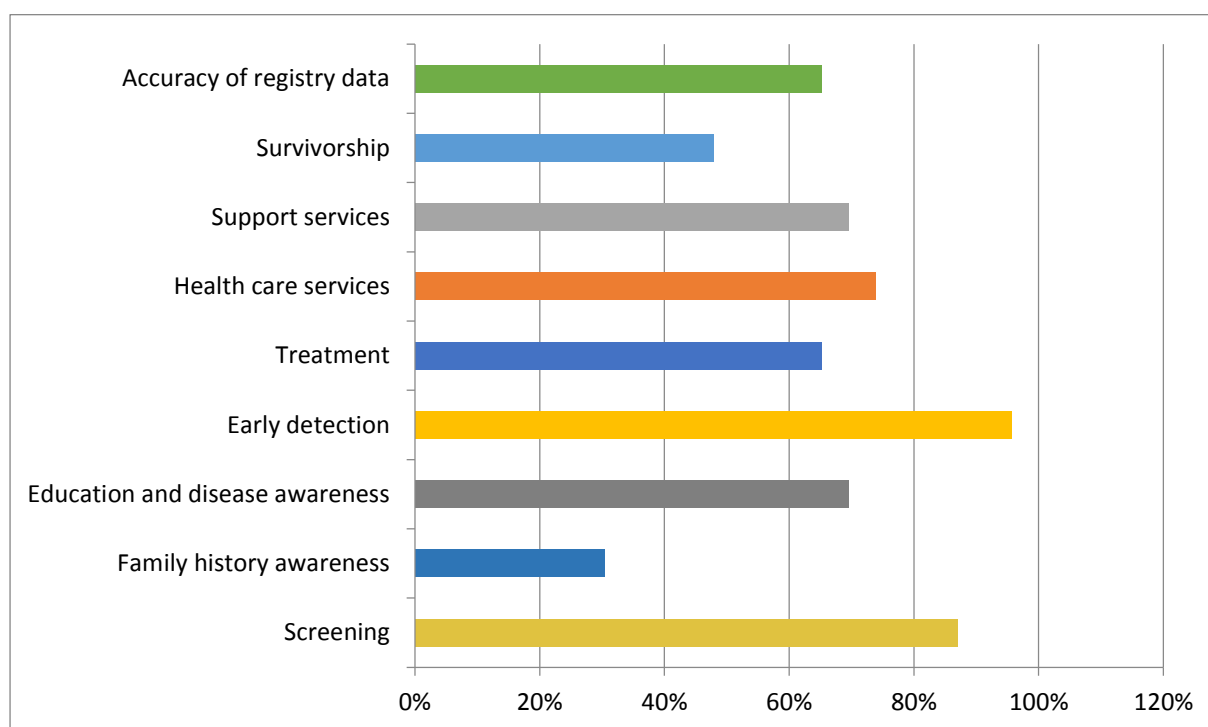
⁴ Percentages have been rounded to the nearest whole number

⁵ To maintain anonymity the number of Aboriginal participants and Torres Strait Islander participants have been combined

- Differences in presentation, treatment, and outcomes between Indigenous and non-Indigenous populations; and
 - Translational (including healthcare-based) research that is likely to have the most impact on breast cancer outcomes.
 - A feasible and actionable plan regarding ways to improve access and encourage uptake of breast screening, engagement in prevention strategies, and access and adherence to treatment.
4. Collaboration and networking.

Research priorities

Respondents selected research priorities that they felt were important and percentages can be seen in graph 2 ⁶. Seven people identified additional priorities, including: access to culturally appropriate information; further understanding of cancer characteristics in Indigenous populations so that screening and early detection can be improved; access and follow up to services, appropriateness of different approaches for Indigenous women; community support and visible ambassadors; and genetics and risk estimation.



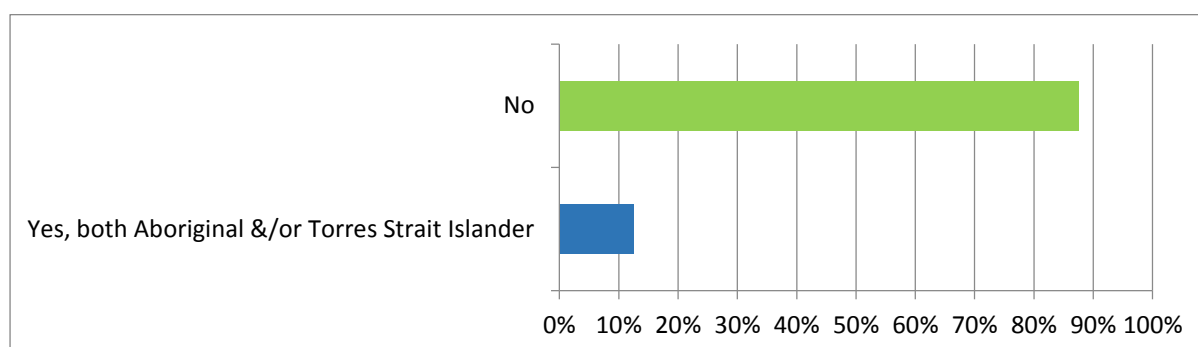
Graph 2: Pre-survey: What do you see as research priorities in this area?

⁶ Please note participants were able to identify more than one category.

5.2 Post round table survey

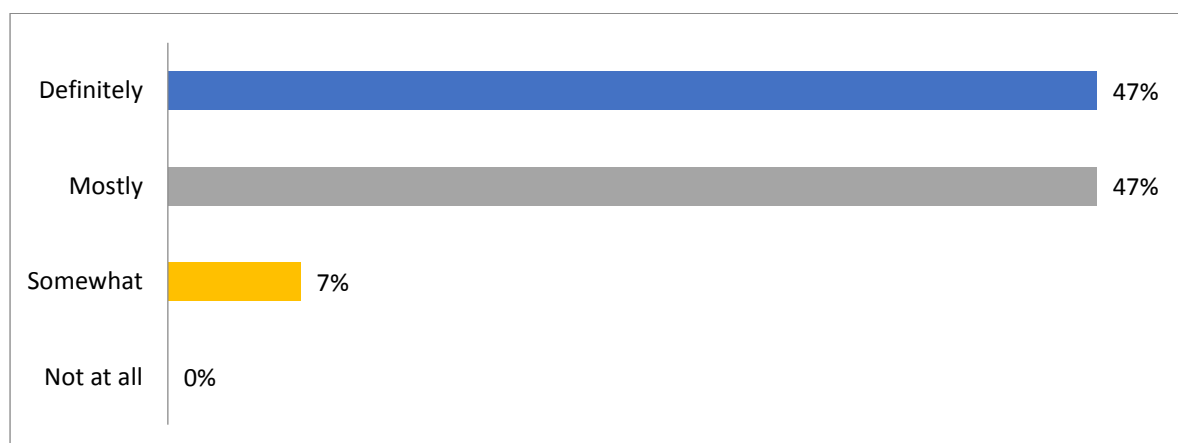
Two days following the Roundtable participants were asked to complete an online survey asking people about research priorities and providing feedback about the event (the survey remained open for two weeks post-roundtable).

Sixteen participants responded to this survey (36.4% response rate). Similar to the pre-survey, the majority of respondents were not Indigenous (see graph 3). Most respondents were researchers/academics (88%, n=14), with three health professionals, one Aboriginal community member and one cancer survivor/ advocate completing the survey.



Graph 3: Post-survey: Are you of Aboriginal and/or Torres Strait Islander origin?

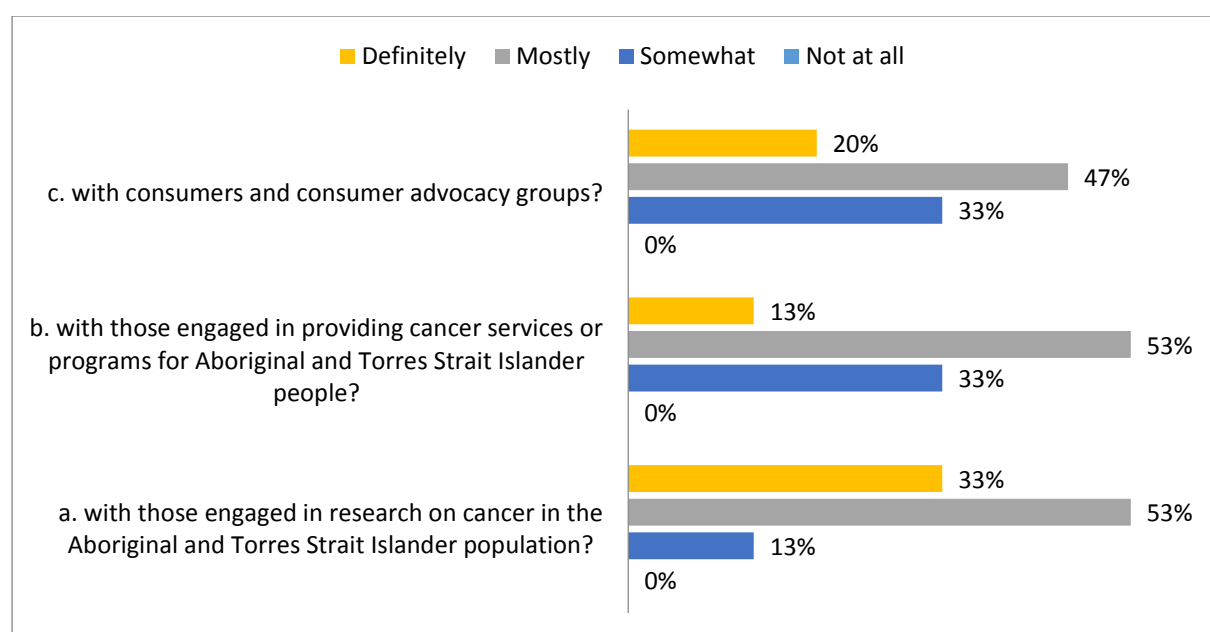
The majority of respondents 'definitely' or 'mostly' found the Roundtable valuable and worthwhile, and one person skipped the question (graph 4). Similarly, most respondents (94%) agreed that the Roundtable had delivered 'mostly' or 'definitely' what they were expecting, with one person considering that their expectations had been 'somewhat' met. Four respondents had previously attended a Roundtable on cancer and Indigenous people and as a result, three of these people indicated they were now collaborating with others as a result of attending these Roundtables. Most respondents (69%) reported that the Roundtable 'definitely' or 'mostly' set out what it achieved to do (i.e., identify a national research agenda specific to breast cancer amongst Indigenous people), and 31% thought it had been 'somewhat' achieved.



Graph 4: Pre-survey: Overall did you find the roundtable valuable and worthwhile

Aspects of the Roundtable considered the most beneficial to respondents were⁷: meeting other participants (88%), networking and collaboration (81%), discussion of strategies, policies and practices (63%), obtaining research/project information (25%), and opportunity to inform others about own work or research (13%).

On a scale of 1 (not at all) to 4 (definitely), the majority of respondents reported that the Roundtable 'mostly' and 'definitely' strengthened relationships with people who: 1) are engaged in research, 2) providing cancer services and programs, and 3) who are consumers or consumer advocacy groups (graph 5).



Graph 5: Pre-survey: Was the roundtable important in strengthening or initiating relationships?

The majority of participants said that would attend a Roundtable like this again in the future (one participant did not answer this question).

Suggestions for how the Roundtable could be improved included:

1. Include a Commonwealth Department of Health representative to discuss what is, or is not, being done at a national level, and what is being planned.
2. Involve more health professionals working with cancer e.g. cancer care nurses, oncologists, surgeons, social workers, indigenous liaison officers to broaden the discussions.

⁷ Please note participants were able to identify more than one category.

3. That there were so many important topics to discuss and that it would have been good to either have more time or to change the format to enable more time for discussion and development of a plan. Specific suggestions to address this were:
 - Reduce the number of presentations by providing delegates with reading material prior to the roundtable. This would ensure that the program was not so rushed and allow more time for discussions, prioritizing research questions and then setting a plan in motion.
 - Hold the meeting over two days. This could be organised so that on Day 1 and Day 2 different topics could be discussed, and those interested in the specific topics could attend on the day most relevant to their interest. For example, Day 1 might be screening and early detection and Day 2 could be treatment and survivorship. Participants could focus for longer on a specific broad area, and self-select which day they would be interested in attending.
4. Make clear how the work towards a research agenda was going to be progressed, as it was not clear who was going to be in a position to execute this or the next steps. There could also have been more discussion of the specifics of research priorities and how to engage in initiating collaborative research in each area.
5. To hear more from the Indigenous women in the room.
6. Make sure that presenters make their talks relevant to the subject/objectives of the day.

Another survey was sent to participants outlining the key research priorities (see sections 4.1.2. and 4.2.2.) and they were asked to indicate areas they were interested in pursuing further. Representatives from a number of organisations professed a willingness to collaborate in future endeavours, including Cancer Australia, Menzies School of Health Research, the University of South Australia, The University of Melbourne, School of Public Health University of Sydney and the national kConFab research consortium, Peter MacCallum Cancer Centre.

6. Summary and conclusions

The NICaN Breast Cancer Research Roundtable provided a forum to discuss, develop, and prioritise a research agenda with the aim of improving outcomes for Indigenous people with breast cancer. Breast cancer survivors and advocates, cancer researchers, government representatives, and health service personnel considered a broad range of topics; the culmination of which was a list of research priorities (see Appendix 4). The overarching themes were (1) the need to enhance early detection, risk management, and screening and (2) to improve cancer treatment uptake and care, and survivorship for Indigenous people. A number of participants agreed to collaborate to further these research agendas

7. References

Australian Bureau of Statistics. Causes of death, Australia: 2012. Canberra: Australian Bureau of Statistics, 2014.

Australian Institute of Health and Welfare & Cancer Australia. Cancer in Aboriginal and Torres Strait Islander people of Australia: an overview. Canberra: : AIHW, 2013.

Garvey G, Cunningham J, Valery C P, Condon J, Roder J, Baillie R, et al. Reducing the burden of cancer for Aboriginal and Torres Strait Islander Australians: time for a coordinated, collaborative, priority-driven, Indigenous-led research program. Medical Journal of Australia. 2011;194.

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8. Appendices

Appendix 1: List of organisations represented at the 2014 roundtable

<i>Organisation/group</i>	<i>Participants</i>
Australian Indigenous Health/InfoNet	1
BreastScreen NT	1
BreastScreen SA	1
BreastScreen WA	1
Cancer Australia	2
Cancer Council NSW	2
Cancer Council Queensland	1
Cancer Institute NSW	1
Deakin University	2
Department of Health and Ageing	1
Department of Health NT	1
Department of Health Victoria	1
GP Down South/Down South Aboriginal Health	1
kConFab	1
Massey University NZ	1
Menzies School of Health Research	8
National Breast Cancer Foundation	3
NICaN Indigenous Cancer Ambassadors	2
Peter MacCallum Cancer Centre	1
Sir Charles Gairdner Hospital WA	1
South Australia Health and Medical Research Institute (SAHMRI)	2
Sydney Breast Clinic	1
The Lowitja Institute	2
University of South Australia	2
University of Sydney	2
University of WA	2
VACCHO	2
WA Centre for Rural Health	2
TOTAL	48

Appendix 2: NICaN Breast Cancer Research Roundtable Agenda

Time	Topic	Speaker
9:30 am	Registration – Tea & Coffee/Morning Tea	
10:00 am	Welcome to the Lowitja Institute Welcome to Country How Menzies School of Health Research is improving cancer outcomes for Indigenous Australians Opening of the National Indigenous Breast Cancer Research Roundtable Outline of the day	Romlie Mokak – the Lowitja Institute Aunty Dianne Kerr Alan Cass – Menzies School of Health Research Honourable Dame Quentin Bryce AD CVO Kate Silburn (Facilitator)
10:20 am	An overview of Indigenous breast cancer research in Australia	David Roder – University of South Australia Suzanne Moore – Menzies School of Health Research
10:40 am	Treatment – An overview (10 mins) Stream 1: National Breast Cancer Screening Program (10 mins) Screening and early detection – barriers to screening and strategies for increasing breast awareness (10 mins) Family history (10 mins)	Rajah Supramaniam – Cancer Council NSW Rachael Anderson – Department of Health Victoria Leanne Pilkington - BreastScreen WA Heather Thorne - Kconfab
11:20 am	Stretch Break - Tea & Coffee	
11:30 am	Stream 2: Supportive Care Needs (10 mins)	Gail Garvey – Menzies School of Health Research
11:40 am	Stream 3: Survivorship Q & A session (15 mins)	Roshi Kamyab – Sir Charles Gairdner Hospital WA Annette Lawrence – breast cancer survivor
11:55 pm	Summary of Current Research Priorities in Breast Cancer and Aboriginal and Torres Strait Islander people	Gail Garvey – Menzies School of Health Research
12:05 pm	Identifying Discussion Streams for Roundtable Groups	Kate Silburn (Facilitator)
12:25 pm	Lunch – including an overview of the Lowitja Institute and design of the new office space	Romlie Mokak – the Lowitja Institute
1:00pm	Stream discussions in groups – topics to be confirmed	All attendees
2:20 pm	Group feedback on priorities	Group Captains
2.50 pm	Afternoon Tea - Tea & Coffee	
3.00 pm	Open discussion	All attendees
3:30 pm	Identify research areas of interest	All attendees
3:45 pm	Closing remarks	Kate Silburn (Facilitator)
4:00 pm	End – Tea & Coffee	

Appendix 3: An overview of Breast Cancer Research in Indigenous Women in Australia Summary Document



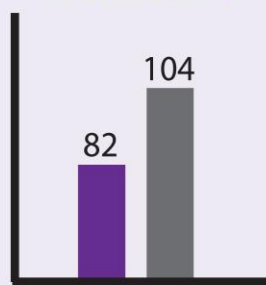
An Overview of Breast Cancer Research in Indigenous* Women in Australia

Background

Breast cancer is the most common cancer experienced by Indigenous women, although rates are lower than those of non-Indigenous Australian women. Despite this, Indigenous women are more likely to die from breast cancer than non-Indigenous women. This pattern has been consistent over a number of years, possibly due to factors such as late diagnosis, lower participation in breast screening programs, lack of access to appropriate services, and because Indigenous women are less likely to complete treatment. Research is needed so that we have a better understanding of breast cancer and how we can improve breast cancer outcomes for Indigenous women.

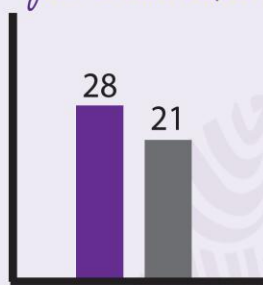
What we know so far...

How many women get breast cancer?



(per 100,000 age-standardised)

How many women die from breast cancer?



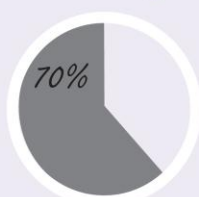
(Five-year BC mortality rate [%])

■ Indigenous ■ Non-Indigenous

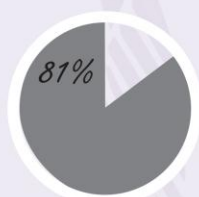


The incidence rate for breast cancer in NT Indigenous women increased by 110% between 1991 and 2005.

Five-year survival



Indigenous



Non-Indigenous

Factors that may... increase breast cancer risk

Alcohol
Poor diet
Family History
Obesity (weight gain) ^
Hormonal factors
Lack of exercise

Younger age of first pregnancy
Multiple pregnancies
Breastfeeding

decrease breast cancer risk

* Aboriginal and Torres Strait Islander people are herein respectfully referred to as Indigenous throughout this publication
^ particularly for postmenopausal women

Appendix 3: An overview of Breast Cancer Research in Indigenous Women in Australia Summary Document Cont.



Indigenous women are more likely to...[#]

- be diagnosed with breast cancer at a younger age
- be diagnosed with advanced breast cancer
- present with larger tumours
- be treated by mastectomy rather than removal of tumour

Indigenous women are...[#]

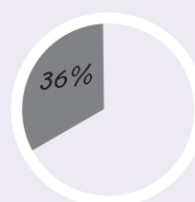
30%
less likely

to be hospitalised
with breast cancer

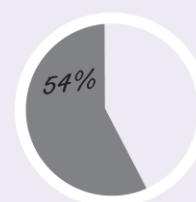
1.3
times

more likely to die
from breast cancer

Mammography Rates



Indigenous



Non-Indigenous

Some issues to improve as we move forward:

- recording of Aboriginal and Torres Strait Islander status in registry and health records
- improve awareness of and participation in screening programs
- cultural acceptability of services (including outreach services)
- our understanding of cultural issues by service providers
- inclusion of Indigenous health workers and representation on governance structures of health services
- our understanding of how diabetes and other health issues might effect cancer treatment and survival
- our understanding of end-of-life cultural and spiritual significance for Indigenous people
- involvement of local Indigenous communities in deciding on service needs and priorities
- transport and accommodation services for women from regional and remote areas
- culturally acceptable information services on the internet
- issues like racism and power imbalance need to be addressed actively

References:

Australian Institute of Health and Welfare & Cancer Australia 2012. Breast cancer in Australia: an overview. Cancer series no. 71. Cat. no. CAN 67. Canberra: AIHW.

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Supramaniam, Gibberd, Dillon, Goldsbury, O'Connell 2014. Increasing rates of surgical treatment and preventing comorbidities may increase breast cancer survival for Aboriginal women. BMC Cancer, 14, 163.

Zhang X, Condon J, Dempsey K & Garling L 2008. Cancer incidence and mortality, Northern Territory 1991-2005. Darwin: Department of Health and Families.

Appendix 4: Summary of Research Priorities Identified by Roundtable Participants

Stream 1: Early detection, risk management and screening

1. Research, programs, and services

- Review and evaluate current services and current knowledge

2. Breast awareness and health literacy

- Develop effective health literacy and communication strategies specific to Indigenous people
- Develop new ways to raise awareness about breast cancer and breast cancer screening
- Evaluate strategies to promote breast awareness, identify those that are effective, and share this knowledge
- Understanding stigma and shame regarding cancer and screening for cancer
- Understand individual, family and community-level factors that influence health seeking behaviours
- Improve earlier diagnosis by exploring ways to encourage medical specialists into remote areas

3. Screening

- Develop a better understanding of the issues that impact on participation in screening and how to address these (enablers and barriers)
- Develop and test alternative service delivery models with attention to how screening services may differ for rural/remote and urban areas

Stream 2: Treatment and supportive care

1. Barriers to accessing and completing treatment

- Gain an understanding of current practice
- Understand the impact of complex health needs, including high rates of comorbidities

2. Culturally appropriate service delivery

- Develop models of care for treatment and support services
- Understand the psychosocial needs of Indigenous women diagnosed with breast cancer and their families, and the best ways to provide supportive care to help people cope after cancer
- Understand, acknowledge, and meet culturally specific needs of Indigenous women during their treatment