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# Sociocultural Influences on Healthcare Inequalities Among Australian Indigenous Breast Cancer Patients

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# Sociocultural Influences on Healthcare Inequalities Among Australian Indigenous Breast Cancer Patients

## Abstract

Healthcare inequalities among Australian Indigenous people are significantly influenced by sociocultural factors. Understanding these influences and potential solutions benefits from insights into behavioural factors in parallel with social and cultural perspectives of beliefs and attitudes. Deeper analysis of breast cancer among Indigenous women is required to better understand factors and solutions to close the inequality gap.

A systematic and critical review of peer-reviewed literature was undertaken using the MEDLINE (Pubmed) electronic database. After inclusion and exclusion criteria were applied, and critical appraisal undertaken, 20 articles were identified that aligned with breast cancer incidence or survival among Indigenous Australians.

The analysis revealed three central themes; pathological factors, cultural factors and social factors. Data linkage strategies reveals inequality in both incidence and 5-year survival for Indigenous breast cancer patients. Both sociocultural behaviours and sociocultural attitudes and beliefs about health, illness and healing contribute to inequality among Indigenous breast cancer patients.

Poorer outcomes relate to Indigenous patients presenting with more advanced disease. Cultural and socioeconomic behaviours, attitudes and beliefs are significant barriers that create disparities between Indigenous and non-Indigenous women's access to and engagement with breast cancer services.

## Acknowledgments

We would like to take the opportunity to acknowledge the First Nations people who are the Traditional Custodians of the Land on which we live and learn. We acknowledge all Indigenous peoples of Australia and all First Peoples of other Lands; and celebrate their enduring connection to Country, knowledge and culture. We pay our respects to their Elders past, present and emerging; and extend that respect to all First Nations peoples. In the spirit of reconciliation, we recognise their struggle for social justice and the need for individual and collective healing.

## Keywords

Indigenous Australian, breast cancer, survival, incidence, inequality

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## Sociocultural Influences on Healthcare Inequalities Among Australian Indigenous Breast Cancer Patients

Healthcare inequity, or opportunity to access healthcare, is influenced by social and cultural factors. Inequality and inequity are interwoven by political and pathophysiological factors, therefore, it is not uncommon for the terms to be used interchangeably. Here, inequality is used to reflect, among Indigenous Australians, a tension between social determinants of health favoured in western medicine and the cultural dimension to health emphasised in Indigenous behaviours. Inequality for Indigenous people in the healthcare system is driven by a combination of implicit and explicit racial bias with extrinsic and intrinsic barriers to accessing healthcare services (*Anderson et al., 2016; Stephens et al., 2005; Shapiro et al., 2006*). For breast cancer, incidence has increased in Australia but the mortality from breast cancer has decreased and survival has increased (*Tapia et al., 2017*). These advances are not, however, evident among Indigenous women.

To further understand inequality, a systematic review of the peer-reviewed literature has been undertaken to provide an evidence-based insight into social and cultural behaviours, beliefs and attitudes that influence inequality for Australian Indigenous women with breast cancer. An objective, evidence-based review of the literature mitigates potential observer effects and bias associated with narrow optics of individual lived experiences.

### Background

#### Indigenous Australian Health Snapshot

While Indigenous Australians comprise 3% of the overall population, they represent a disproportionately high proportion of rural (8%) and remote (18-47%) communities where healthcare services and expertise are less advanced or available compared to metropolitan centres (2%) (*AIHW, 2020*). While there are a number of initiatives aimed at servicing rural and remote communities, and Indigenous communities specifically, specialised health services in Australia are distributed based on population density. Even a large rural community can be many hours from specialised medical services and remote communities may only be available under emergency air service transport. This is typically compounded by under-representation of Indigenous healthcare workers. Indigenous Australians have a higher burden of disease (2.3 fold) compared to non-Indigenous Australians with 67% living with chronic disease and 33% living with three or more concurrent diseases (comorbid) (*AIHW, 2020*). There are a number of cultural, social, economic and geographic barriers associated with lower levels of access to healthcare services and compliance with treatment for Indigenous Australians (*AIHW, 2020; Reath & Carey, 2008*). There is significant scope to provide opportunities to Indigenous Australians across the gamut of socioeconomic metrics (*Tapia et al., 2017; AIHW, 2020; AIHW, 2014; Bainbridge et al., 2015; Currie, Wheat & Wess, 2018; Currie & Currie, 2022*).

#### Breast Cancer

Among Indigenous Australians, cancer is the leading cause of disease-based death, accounting for 23% of deaths (*AIHW, 2020*). Breast cancer is the most common cancer among Indigenous women in Australia (*Moore et al., 2015*). While the incidence of some cancers, including breast cancer, are reported to be lower in Indigenous Australians than in non-Indigenous Australians, mortality rates

are 2-2.5 times higher ( *Tapia et al., 2017; AIHW, 2020; Valery et al., 2006*). This is likely to reflect lower access to or uptake of appropriate treatment combined with the effects of higher rates of comorbidity (eg. heart disease and diabetes).

Compared to non-Indigenous Australians, Indigenous cancer patients have statistically lower use of chemotherapy ( $P < 0.0001$ ), radiation therapy ( $P = 0.039$ ), surgery ( $P < 0.0001$ ) and intention to treat ( $P < 0.0001$ ) ( *Valery et al., 2006*). Indigenous cancer patients are also statistically more likely to present with 1 or more comorbidities than non-Indigenous cancer patients ( *Valery et al., 2006*). Adjusted for age, cancer stage, comorbidities and treatment, Indigenous cancer patients are 1.2 to 1.3 times more likely to die than non-Indigenous cancer patients and the mean time to death is shorter for Indigenous cancer patients (251 days) than non-Indigenous cancer patients (383 days) ( *Valery et al., 2006; Christie et al., 2023a*). Discordance between westernised health and cultural values, socioeconomic factors and healthcare inequalities combined with more advanced cancer stage at diagnosis, reduced access to and uptake of treatments, and higher rates of comorbidity contribute to cancer survival disparities. Importantly, while the Federal Governments 'closing the gap' strategy has improved many health-related indicators over the last few decades, cancer has shown increasing incidence, lower screening rates, advanced presentation stage and poorer survival for Indigenous Australians compared to non-Indigenous Australians ( *AIHW, 2020*).

Generally, the incidence of breast cancer among Indigenous women (84.7 per 100000) is reported to be lower than in non-Indigenous women (115.0 per 100000) ( *Moore et al., 2015; Valery et al., 2006; Christie et al., 2023a; Pilkington et al., 2017*). There are a number of causes of this observation that under-represent breast cancer among Indigenous women in Australia. Indigenous women confront other causes of premature death at younger ages and lower rates of access to and utilisation of screening programs ( *Tapie et al., 2017; Moore et al., 2015*). Protective factors may reduce the incidence of breast cancer in Indigenous Australians including; lower rates of nulliparity (never birthing a child), earlier age of first full-term pregnancy, and longer breastfeeding periods ( *Tapie et al., 2017; Moore et al., 2015*). Despite these explanatory factors, breast cancer rates in Indigenous women remain underestimated due to deficiencies in data collection ( *Tapie et al., 2017*).

## Method

A systematic review of the peer-reviewed literature was undertaken and critically evaluated to ensure relevance and reliability. Since the exploration related specifically to health outcomes, the search was restricted to the electronic database MEDLINE (PubMed) (figure 1). PubMed was searched using 'Indigenous' and 'Australia' as search terms in combination with the specific search term 'breast cancer'. Literature that met the inclusion criteria were English language, published in the last 10 years (preceding the end of 2023), peer reviewed, and indexed in Medline.

Of 85 articles located using the primary search, 52 met the inclusion criteria (figure 1). Papers were excluded ( $N = 22$ ) if they were editorials or letters to the editor or if they did not have a specific focus on Indigenous Australians and breast cancer. The 30 remaining articles reflected a focus on either Australian Indigenous people or breast cancer. These 30 abstracts were evaluated for alignment with the breast cancer survival research scope which excluded a further 10 articles. Analysis of the remaining 20 papers indicated all (table 1) met the minimum standards of quality using the preferred reporting items for systematic review and meta-analysis (PRISMA) protocol ( *Moher et al., 2015*). Thematic analysis was undertaken using the 6 step process ( *Naeem et al., 2023*) which revealed

three central themes related to survival among Indigenous Australian breast cancer patients; pathological factors, cultural factors, and social factors (figure 1).

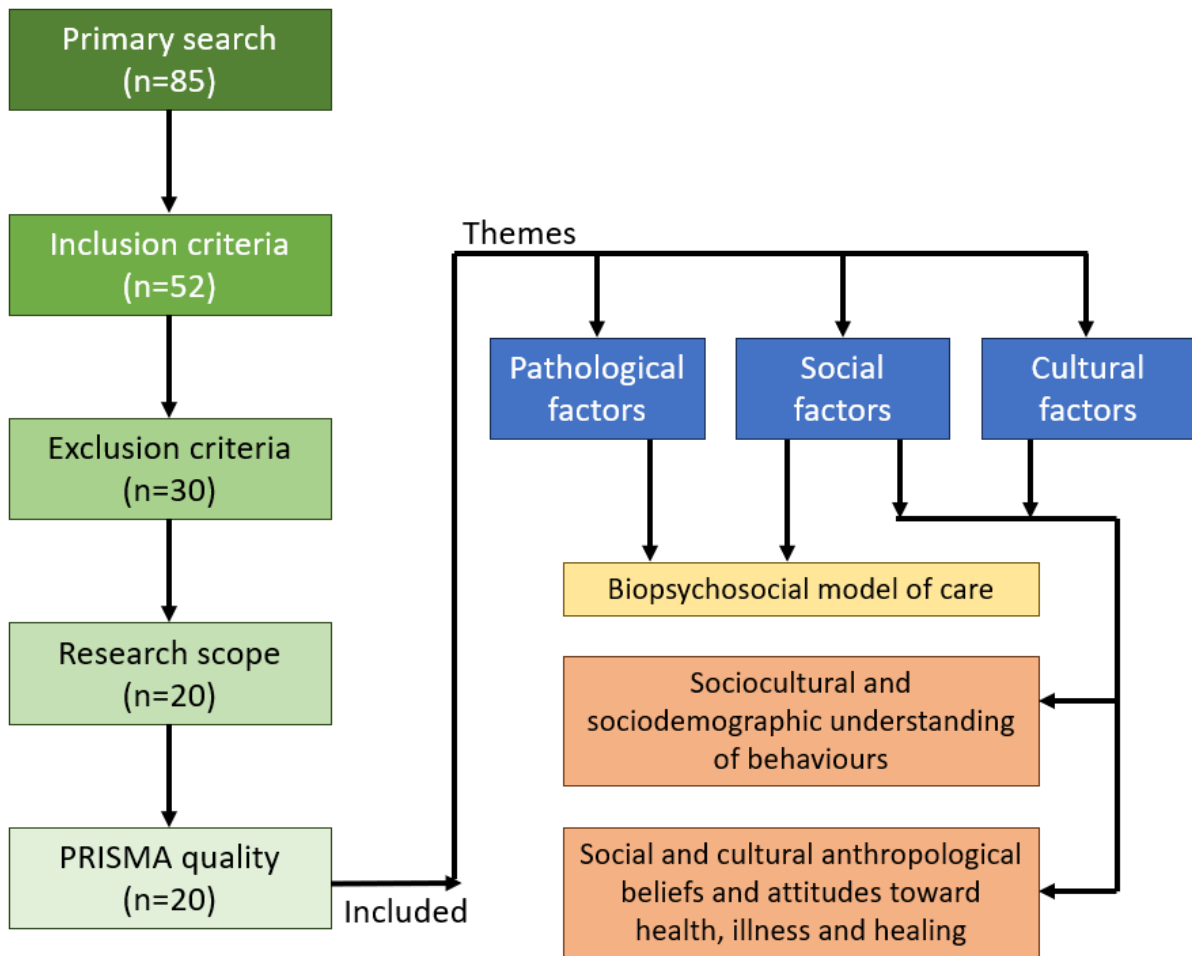


Figure 1: Flow chart demonstrating search criteria, themes and connection.

**Table 1: Results of systematic literature search and critical evaluation. All articles included satisfied the PRISMA standards.**

Citation	Abbreviated title	Pathological factors	Cultural factors	Social factors
<i>Reader et al., 2020</i>	Do histopathological features of breast cancer in Indigenous women explain survival disparity?	✓		
<i>McClean et al., 2019</i>	The distribution and determinants of mammographic density measures in Western Australian aboriginal women.	✓		
<i>Tervonen et al., 2019a</i>	Differences in cancer incidence by age at diagnosis between Aboriginal and non-Aboriginal people.	✓		
<i>Tervonen et al., 2017</i>	After accounting for competing causes of death and more advanced stage, do Indigenous peoples with cancer still have worse survival?	✓		
<i>Mencel et al., 2023</i>	Breast cancer characteristics and pathological prognostic determinants in indigenous Australians	✓		
<i>Christie et al., 2021</i>	What Is the evidence globally for culturally safe strategies to improve breast cancer outcomes for Indigenous women in high income countries?		✓	
<i>Adams et al., 2015</i>	Use of traditional Indigenous medicine and complementary medicine among Indigenous cancer patients.		✓	
<i>Ung, 2022</i>	Towards better breast cancer outcomes for Indigenous populations in high-income countries with highly developed health systems.		✓	
<i>Tapie et al. 2019</i>	Breast screening attendance of Aboriginal and Torres Strait Islander women.		✓	✓
<i>Pilkington et al., 2017</i>	Perspectives of Aboriginal women on participation in mammographic screening.		✓	✓
<i>Dasgupta et al., 2017</i>	Variations in outcomes for Indigenous women with breast cancer in Australia.		✓	✓
<i>Condon et al., 2016</i>	Trends in cancer incidence and survival for Indigenous and non-Indigenous people.		✓	✓
<i>Tervonen, Purdie &amp; Creighton, 2019b</i>	Using data linkage to enhance the reporting of cancer outcomes of Aboriginal and Torres Strait Islander people.		✓	✓
<i>Christie et al., 2022</i>	Improving breast cancer outcomes for Aboriginal women: a mixed-methods study protocol.		✓	✓
<i>Walpole et al., 2023</i>	Development of a key performance indicator for breast cancer in Queensland, Australia		✓	✓
<i>Youl et al., 2016a</i>	A systematic review of inequalities in psychosocial outcomes for women with breast cancer according to residential location and Indigenous status.			✓
<i>Garvey et al., 2016</i>	Health-related quality of life among Indigenous Australians diagnosed with cancer.			✓
<i>Youl et al., 2016b</i>	The Impact of rurality and disadvantage on the diagnostic interval for breast cancer.			✓
<i>Banham et al., 2019</i>	Disparities in breast screening, stage at diagnosis, cancer treatment and risk of cancer death.			✓
<i>Baum, 2023</i>	Exploring Disparities in Breast Cancer Screening: An Ecological Analysis of Australian			✓

## Results

### Pathological Factors

Given the literature suggests Indigenous women have lower incidence of breast cancer but higher mortality from breast cancer than non-Indigenous women (*Christie et al., 2021*), an understanding of the pathological nature of disease is important. For breast cancer, a key pathological identifier for cancer aggressiveness is whether the cells are receptor positive or receptor negative (*Read et al., 2020*). This means that the breast cancer cells, if positive, have an abundance of proteins (eg. hormones or growth factors) on the cell surface that help the cancer cell grow and multiply. Among breast cancer patients in the Northern Territory, Read et al. (*Read et al., 2020*) reported that there was no statistically significant difference in oestrogen receptor expression between Indigenous and non-Indigenous women ( $P=0.850$ ). There was, however, statistically higher representations of late-stage breast cancer ( $P=0.030$ ) and metastatic spread ( $P=0.002$ ) at presentation for Indigenous women compared to non-Indigenous women. In another study, there were no statistically significant differences in oestrogen receptor expression ( $P=0.138$ ) or progesterone receptor expression ( $P=1.0$ ) between Indigenous and non-Indigenous breast cancer patients. This suggests that, despite poorer outcomes, there is no difference in hormone receptor status between Indigenous women with breast cancer and non-Indigenous women.

Breast tumour proliferation is strongly linked to cell surface growth receptors. A statistically significant higher representation of human epidermal growth factor receptor 2 (HER2) expression among Indigenous (51% positive) compared to non-Indigenous (26% positive) breast cancer patients ( $P<0.001$ ) has been identified (*Read et al., 2020*). HER2 is a hormone that drives cell growth and division which results in more aggressive disease. Mencil et al. (*2023*) similarly reported increased HER2 positive tumours contributing to larger and more advanced disease. This is consistent with Indigenous breast cancer patients, compared to non-Indigenous breast cancer patients, presenting with larger tumour burden and greater lymph node burden (*Read et al., 2020; Dasgupta et al., 2017*). Tumour phenotyping allowed identification of a disproportionate incidence of HER2 positive cancers which will contribute to more advanced stage at presentation and poorer outcomes; independently of socioeconomic, social and cultural factors. Conversely, non-Indigenous breast cancer patients were more likely to present with phenotypes associated with better prognosis (eg. luminal).

The NSW Cancer Registry was used to analyse Indigenous Australian data from 2001 to 2014, including for breast cancer (*Tervonen et al., 2019a*). The specific aim was to better understand screening programs. Of note was that screening programs are triggered by specific age demographics (50-74 years for breast screening) which fails to account for the earlier presentation (younger age) of breast cancer in Indigenous women (*Tervonen et al., 2019a*). For Indigenous women, the data revealed that 30.6% of breast cancer cases were diagnosed before 50 years (compared to 22.8% for non-Indigenous women). While lowering the screening age for Indigenous women could increase false positive studies, the potential value in earlier detection and greater participation in breast screening could positively impact outcomes and survival. Tervonen et al. (*2019a*) conclude that the breast screening age should not be different for Indigenous and non-Indigenous Australians, nor lowered, on the basis of a lack of evidence supporting improved breast cancer mortality for women aged 40-49 years with breast screening. Yet in Australia and in other developed countries, breast screening age is selectively reduced for women with higher risk of early disease (eg. family history).

Failure to recognise unique characteristics of breast cancer in Indigenous women contributes to healthcare inequality. Indeed, a recent review of policy by experts concluded (recommendations) that for Indigenous women, breast screening should be free and available at an earlier age (from 40 years) (*Christie et al., 2023a*).

While uptake of breast screening is a recognised issue among Indigenous women, even with increased screening participation, there are a number of potential confounders to improved outcomes. Breast density is associated with an increased risk of breast cancer but breast density also decreases the efficacy of mammographic screening (*Mclean et al., 2019*). Little has been published on breast characteristics of Indigenous Australian women. While Indigenous women have larger breast area than non-Indigenous women (*Mclean et al., 2019; Tervonen et al., 2019a*), breast density and the volume of high-density breast tissue is lower for Indigenous women age matched to non-Indigenous women (*Mclean et al., 2019*). In fact, Indigenous women comprise a disproportionately high portion of the very low-density area of breast. Lower breast density means Indigenous women could have higher efficiency breast screening which could partially offset poorer outcomes and survival. Less dense breasts among Indigenous women also debunks the breast density-based justification of Tervonen et al. (*2019a*) for prohibition of breast screening in younger women (pre 50 years). That prohibition was based in denser breasts of pre-menopausal women absorbing higher radiation doses.

### **Cultural Factors**

Cultural behaviours and attitudes toward health, illness and healing are factors that impact the understanding and management of cancer but are also intertwined with historical, social, economic and political factors (*Shahid et al., 2009*). Key cultural factors to consider are summarised in table 2. Interestingly, a qualitative research study was undertaken to explore Indigenous Australian perceptions of mammograms and revealed that fear of results and shame were significant cultural barriers to uptake of breast screening (*Pilkington et al., 2017*) and this is reflected in reflective experiences in later work (*Christie et al., 2023b*). Other key cultural barriers related to lack of Indigenous cultural knowledge and understanding among healthcare providers and policy makers, are tabulated in Table 2 (*Sahid et al., 2017*).

**Table 2: Key cultural factors to consider for breast cancer among Indigenous women (*Shahid et al., 2009*).**

Factor	Consideration
Spirituality	Among Indigenous people may drive a fatalistic approach to breast cancer. That is, breast cancer is a punishment from the spirit world which can see individuals accept the disease, not seek help, feel ashamed and thus delay any diagnosis and resist treatment.
Fatalism	Is also linked to fear and a sense that there are no treatment options, even if desired. Breast cancer being a death sentence is a view that can be a barrier to Indigenous women seeking medical help or treatment. The value of early detection for improved outcomes, longevity and potential cure needed to be crafted in a culturally sensitive way to reverse this issue.
Passivity	Fatalism is conflated by concurrent passivity where individuals assume nothing can be done to prevent or change the course of breast cancer. At play in fatalism is the power distance index, where fatalism among Indigenous women also increases the resistance to the hierarchy of power associated with westernised and institutionalised medicine; an important cultural dimension.
Unrealistic expectation of outcomes	Cancer treatment is not binary in outcomes (cure versus death) and comorbidity complicates outcomes in Indigenous people. Recurrence or death due to breast cancer then undermines trust in the healthcare system. A probabilistic approach to outcome communication is not consistent with Indigenous culture.
False perceptions	The reluctance to seek help may be driven, in part, by perceptions that cancer is contagious and the subsequent fear of individuals being isolated or shamed from their communities. This is linked to a general lack of understanding of cancer, including warning signs and the role of screening in breast cancer.

There remains a lack of cultural safety within the healthcare setting (*Currie & Currie, 2022; Christie et al., 2023a; Christie et al., 2021*). This includes historical and institutional discrimination, implicit and explicit racism, absence of culturally appropriate care, and lack of culturally appropriate educational resources and health promotion (*Christie et al., 2021*). These factors strongly influence attitudes and beliefs about health, illness and healing within westernised health.

An important cultural consideration is the connection between Indigenous Australians and the land, including traditional or bush medicines. Enculturation or adoption of cultural norms associated with bush medicine is consistent with the holistic approach Indigenous Australians adopt for health and wellbeing inclusive of spiritual and social support (*Adams et al., 2015*). Among Indigenous cancer patients in Queensland (24% breast cancer), only 3% reported using bush medicine to manage their cancer (*Adams et al., 2015*). There was, however, no accounting for the Indigenous cancer patients who opt out of cancer care and treatment who may have a higher reliance on traditional use of native botanicals for healing; bush medicine. Thus, Indigenous use of bush medicine is likely to be underestimated. Generally, cultural beliefs are thought to be competitive with appropriate (westernised) cancer treatment. The low uptake of bush medicine for cancer patients signals recognition that cancer is seen as 'a death sentence', 'incurable' or a product of colonisation requiring western medicine.

Li (2017) also identified cultural barriers as the main cause of poorer health outcomes among Indigenous Australians. At the core of cultural barriers lies differences in beliefs, health literacy and understanding, and interpretations associated with identity, value and health (Prior, 2005). Treatment compliance among Indigenous women is reduced by a fatalistic perspective on breast cancer combined with cultural challenges of treatments (Valery et al., 2006; Li, 2017); captured by the sentiment “take my cancer but leave me whole” (Prior, 2005). The barriers and fatalistic beliefs undermine trust with western healthcare, delay presentation, decrease utilisation of screening and decrease compliance with treatments (Li, 2017). Communication should be undertaken in a culturally sensitive and culturally competent manner but recognition is needed that communication and cultural sensitivity are more than simply the language used.

A number of culturally appropriate strategies have been implemented to address social, cultural and financial sources of inequality among Indigenous women with breast cancer (Christie et al., 2022). Success, however, is dependent on partnership with Indigenous people using a co-designed strategy and community mapping (Christie et al., 2022). Ung (2022) identified pinch points for potential inequality for Indigenous patients. Inequality is driven by differences in or barriers to (Ung, 2022; Anderson et al., 2021):

- Perception of need,
- Trust of system, procedures / treatments, and health workforce,
- Access to medically and culturally appropriate care,
- Access to specialist services,
- Availability, affordability and acceptability of culturally appropriate care,
- Access to services of an elective or non-urgent medical nature, and
- Outcomes.

Perhaps the way forward to enhance cultural safety for Indigenous people within a westernised health system could adopt the ‘two-eyed seeing’ philosophy emerging in Canada (Wieman & Malhotra, 2023). Indeed, the philosophy is consistent with strategies for Indigenous Australian health and the philosophy of ‘nothing about us without us’. Specifically, informing Indigenous health and health strategies through the optics of Indigenous knowledge and ways of knowing (one eye) in tandem with the optics drawn from western medicine expertise (second eye) for a vision of embracing both respectfully (two-eyed seeing).

### Social Factors

The 5-year unadjusted survival for Indigenous women with breast cancer has been reported as 6-15% lower than non-Indigenous women (Dasgupta et al., 2017) consistent with other reports (Tervonen et al., 2017; Condon et al., 2016). Adjusting for comorbidity, stage at diagnosis, socioeconomic factors and treatment factors, however, there were no differences noted (Dasgupta et al., 2017). This suggests disparities in survival can be addressed by socio-cultural inequalities in healthcare. Strategies to increase accessibility of breast screening among Indigenous communities has seen a 5% increase in screening participation among 50-69 year-olds (Tapia et al., 2019). Strategies have included mobility of screening services into under-serviced communities, culturally appropriate health promotion and building the Indigenous workforce (Tapia et al., 2019). Of particular importance are the multi-faceted strategic approaches aimed at improving accessibility independently of cultural or linguistic diversity, rurality, socioeconomic status and Indigeneity

(*Tapia et al., 2019*). This is important because there remain significant social, demographic and geographic factors that influence breast screening participation among Indigenous women (*Baum, 2023*).

A qualitative research study explored Indigenous Australian perceptions of mammograms and revealed that competing interests (too busy) and geographic isolation or lack of transport were significant social barriers to uptake of breast screening (*Pilkington et al., 2017*). Other key social barriers related to lack of trust for mammogram, health services or health workers, breast cancer awareness and education, and local support for Indigenous women (especially by female Indigenous health workers) (*Pilkington et al., 2017*). Importantly, strategies need to make breast cancer evaluation and treatment less intimidating and should be undertaken as inter-cultural initiatives.

There are also social factors that undermine compliance with breast cancer treatment among Indigenous women. In a large study of over 8000 stage I, II and III breast cancer patients in Queensland, 32% took longer than 37 weeks to complete treatment (*Walpole et al., 2023*). Treatment beyond 37 weeks was associated with poorer outcomes with 40% higher risk of death associated with treatment beyond 37 weeks (*Walpole et al., 2023*). A number of sociodemographic and socioeconomic factors contribute to an increased likelihood of treatment extending beyond 37 weeks (eg. living in a disadvantaged area or multiple comorbidities) which compound the increased likelihood ( $P=0.002$ ) that Indigenous women (52%) compared to non-Indigenous women (31%) will take longer than 37 weeks to complete treatment.

In Queensland Australia, a longitudinal study of more than 3000 newly diagnosed breast cancer patients was undertaken to identify key factors that delay diagnosis and risked poorer outcomes (*Youl et al., 2016b*). The key barriers included competing interests (eg. work or family responsibilities), fear or anxiety (outcome and healthcare system), system failures (eg. lack of access to services, appointments or transport), and low priority (aware of symptoms but monitoring or waiting). Each of these factors are inherent across cultural and social groups but are particularly endemic among Indigenous Australians (*Youl et al., 2016b*). Banham et al. (2019) adopted a matched-cohort approach using Indigenous and non-Indigenous breast cancer data from South Australia and revealed that Indigenous women with breast cancer were over 8 times more likely to live in the most disadvantaged communities. Indigenous women were 3.3 times more likely to have a delay in being diagnosed with breast cancer than non-Indigenous women (*Youl et al., 2016b*). A delay of 12 weeks translates to a 12% reduction in 5-year survival compared to a delay less than 12 weeks (*Youl et al., 2016b*).

In an effort to better understand disparities in cancer outcomes for Indigenous Australians, Garvey et al. (2016) examined health-based quality-of-life factors. The median quality-of-life scores were higher than the general population (0.73 versus 0.62) for Torres Strait Islander people but lower (0.57 versus 0.62) for Aboriginal people. Specifically for breast cancer, the highest quality-of-life score was recorded compared to other cancer types (*Garvey et al., 2016*). Interestingly, there were no differences in quality-of-life scores associated with cancer stage or treatment approaches. The major limitation of this study was that the quality-of-life metrics did not reflect cultural and spiritual wellbeing typically a priority among Indigenous communities. Health and wellbeing among Indigenous Australians tends to be more holistic with an emphasis on community (*Garvey et al., 2016*) which are not well aligned with the traditional multi-dimensional quality-of-life tool that focusses on psychometric utilities.

Indigenous Australians continue to be under-recorded in health data collection (*Tervonen et al., 2019b*). This results from poor communication, poor cultural awareness, racism and discrimination, and inherent limitations associated with identity tracking (*Tervonen et al., 2019b*). Data linkage initiatives for the NSW Cancer Registry connect multiple sources of information to create a richer database for each person. These were evaluated and demonstrated the magnitude of potential under-estimation of cancer cases. Data linkage methods resulted in a 55% increase in Indigenous cancer patient numbers and a 50.3% increase in the number of breast cancer cases among Indigenous women (*Tervonen et al., 2019b*). The net effect of this strategy is that the previously discussed lower breast cancer rates among Indigenous women compared to non-Indigenous women may be a reflection of data inconsistencies. After data linkage adjustments, breast cancer rates for Indigenous women are 161.1 per 100000 (up from 105.2 per 100000) compared to 120.8 per 100000 for non-Indigenous women (*Tervonen et al., 2019b*).

### Discussion

Healthcare equality is generally viewed as access to health services regardless of social, economic, demographic or geographic factors. It is not surprising that efforts for “closing the gap” on Indigenous health inequality have largely failed because there is little accommodation for cultural factors that reside outside the western medicine paradigm. Cultural dimensions, social identity and community combined with attitudes toward health, illness and healing, spirituality and beliefs shape the cancer journey for Indigenous women and strongly influence perspectives, knowledge and understanding about cancer.

Importantly, communication needs an understanding of cognitive approaches to psychology and accommodate differentials in health literacy, cognitive bias and differences in “ways of knowing” and learning (*8 ways, 2011*). While Indigenous language and the more than 100 dialects are a linguistic and cultural barrier to healthcare equality, the language itself is but a fraction of the barriers to cultural safety in the healthcare setting. A key part of that is cultural identity and the poor representation of Indigenous people in the health workforce undermines trust and cultural safety (*Li, 2017*). The expression “nothing about us, without us” emerged because well intended “closing the gap” policies developed for Indigenous people by non-Indigenous people fails to identify and address the actual barriers.

Indigenous views of health are holistic in nature, encompassing the health and wellbeing of people, animals, and environment (*Riley et al., 2021*). This requires healthcare approaches to align with culture and community, and with Indigenous ways of knowing (*Riley et al., 2021*). This holistic approach does not typically fit well in the westernised medicine paradigm and contributes to widening the healthcare inequality gap. For Indigenous women, the breasts represent womanhood, sexuality, reproduction and nurturing of children (*McMichael et al., 2000*) which is consistent across cultures (*Webb, Jacox & Temple-Oberle, 2019*) and reflected in Indigenous art. The breast is a private part of the body and relates to “women’s business” (*Christie et al., 2023a*). These factors can represent a barrier for screening, diagnosis and treatment compliance. For Indigenous women with breast cancer, diagnosis brings pain, fear and shame which, combined with fatalistic spirituality, delays screening (*Tapie et al., 2017*). This highlights the need for culturally appropriate strategies for cancer detection and treatment. This discussion is consistent with the cultural determinants of health (attitudes and behaviours) identified for Indigenous Australians; family and community, country and place, cultural identity, and self-determination (*Verbunt et al., 2021*).

Depending on individual levels of Indigenous cultural and spiritual immersion, Indigenous breast cancer patients may adopt a holistic perspective to wellbeing that demands support for community connection, spirituality and identity through the cancer journey (*McLennan & Khavarpour, 2004*). *Prior (2009)* reported ambivalence toward cancer among Indigenous women with breast cancer and this was linked to fear, mistrust, lack of understanding, and access difficulties. Central to this ambivalence is a psychosocial connection between colonisation and cancer (*Prior, 2009*). Early detection of breast cancer increases survival with 5-year survival for stage I breast cancer being 88% but stage IV just 15% (*Youl et al., 2016b*). It is imperative, therefore, to identify and resolve sociocultural and psychosocial barriers to healthcare inequality among Australian Indigenous breast cancer patients. Western medicine has evolved with varying emphasis on evidence-based care to patient-centred care and now person-centred care (*Kerin, 2020*). Person-centred care accommodates individual nuances to provide a holistic style of patient care. Indigenous health inequalities, however, require an evolution to a “culture-centred” approach to care (*Prior, 2009*). Consistent with co-design and the mantra “nothing about us, without us”, it is crucial that any culture-centred care approach is driven bottom up rather than imposed top down. Co-design is an important strategy to not only drive collaboration between service providers and service users but also to ensure sociocultural behaviours and attitudes are understood and accommodated in building strategy. Social and cultural factors contribute significantly to increased breast cancer risk factors (table 3), rather than pathological or ethnicity factors alone, demanding understanding for effective strategy development.

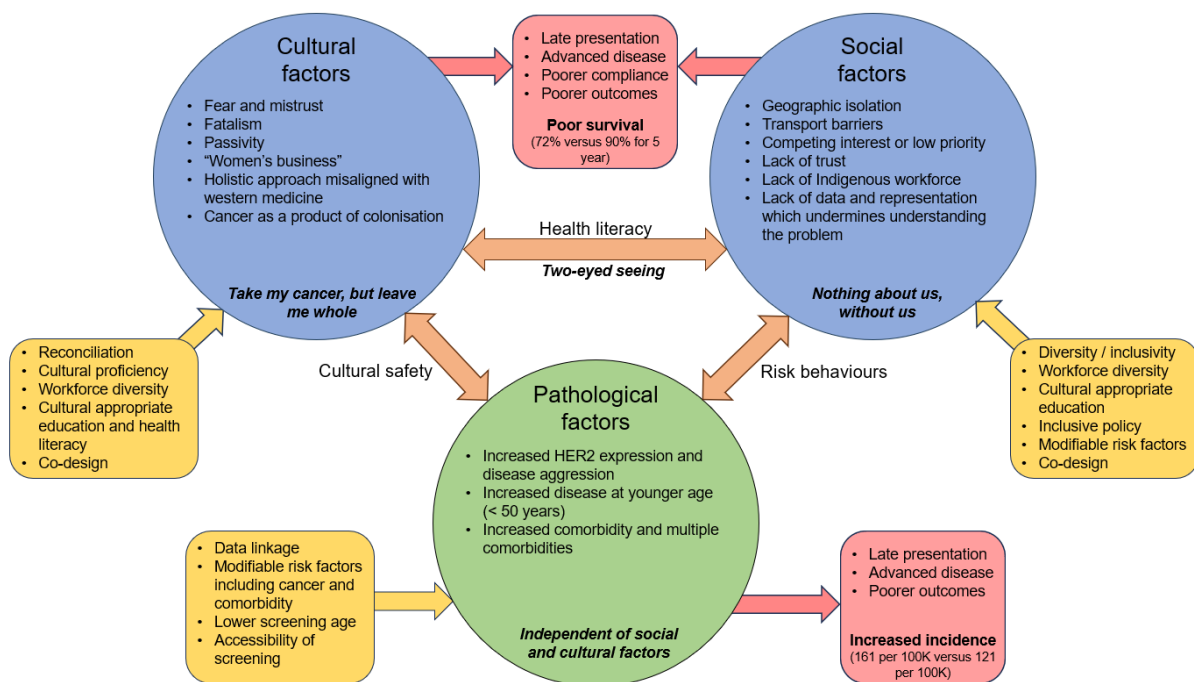
**Table 3: Key factors among Indigenous and non-Indigenous breast cancer patients in Australia (Tapia et al., 2017; AIHW, 2020; Pilkington et al., 2017; Read et al., 2020; Tervonen et al., 2017; Banham et al., 2019).**

Factor	Consideration
Breast cancer mortality	Indigenous women have a higher mortality rate (26.7 per 100000) than non-Indigenous women (23.9 per 100000)
Age at presentation	Indigenous women are twice as likely as non-Indigenous women to present under 50 years. Younger presentation is typically associated with more aggressive disease and poorer survival.
Type of breast cancer	Indigenous women have a statistically higher representation of human epidermal growth factor receptor 2 (HER2) expression (51% positive) compared to non-Indigenous (26% positive) breast cancer patients ( $P < 0.001$ ). This means Indigenous women have more aggressive forms of breast cancer.
Breast cancer stage	Indigenous women have a statistically higher representation of late-stage breast cancer ( $P = 0.030$ ) than non-Indigenous women; decreasing treatment efficacy and survival. Indigenous women are 1.6 times more likely than non-Indigenous women to present with advanced breast cancer and this is particularly high for those under 50 years of age.
Metastatic spread	Indigenous women have a statistically higher representation of metastatic spread ( $P = 0.002$ ) than non-Indigenous women; decreasing treatment efficacy and survival. Standardised for stage, mortality among Indigenous women is 5 times higher than non-Indigenous women when presenting with metastases.
Mammographic screening	Indigenous women have lower uptake of screening programs; 38% for mammogram screening compared to 54% in non-Indigenous Australians. Non-Indigenous women are 3 times more likely to have breast screening than Indigenous women with breast cancer.
Comorbid disease	Indigenous women present with greater comorbidities which can limit treatment options or treatment outcomes.
Barriers to treatment	Indigenous women confront greater barriers to access of appropriate treatment due to geographic remoteness which decreases survival outcomes. Non-Indigenous women are twice as likely to have had breast cancer treatment than Indigenous women with breast cancer.
Treatment	Non-Indigenous women were 3 times more likely to have breast surgery for treatment of breast cancer than Indigenous women. Indigenous women are 2.5 times more likely to have the breast surgically removed or total mastectomy than non-Indigenous women. Non-Indigenous women are 5 times more likely to received chemotherapy compared to Indigenous women with breast cancer.
Compliance factors	Indigenous women are more likely to confront cultural or socioeconomic factors that decrease uptake of or compliance with treatments.
Hospitalisation	Non-Indigenous women are 4 times more likely to be hospitalised for breast cancer compared to Indigenous women with breast cancer.

## Recommendations

There are a number of internal (patient) and external (system and workforce) factors that drive inequality among Indigenous breast cancer patients. To develop and implement corrective strategy, however, an understanding of the foundations on which inequality lies is required. While cultural, geographic, social and socioeconomic factors demand attention in addressing inequality among Indigenous breast cancer patients in Australia, success is contingent on correction of deeply rooted injustice and bias in the healthcare system and more broadly in the community. Historical dispossession, abuse, explicit and implicit racism, historical and institutionalised bias, and discrimination are foundations of healthcare inequality and require resolution through reconciliation, inclusivity, diversity and cultural competence before strategies targeting cultural and social dimensions of healthcare inequality can be effective.

Understanding both sociocultural behaviours, attitudes and beliefs about health, illness and healing (*Currie, 2022*) are required to address inequality among Indigenous breast cancer patients. Strategies could improve Indigenous patient outcomes by decreasing the denominator or increasing the numerator (or both). Improving survival (numerator) by addressing sociocultural barriers (attitudes and beliefs) to breast cancer care among Indigenous women will significantly improve overall performance indicators and address inequalities. Decreasing the incidence of breast cancer by targeting modifiable risk factors linked to sociocultural factors (behaviours) could also improve overall performance indicators (figure 2). Any strategy should not be based on any assumptions associated with Indigenous women adhering to guidelines and should include consultation with Indigenous women (*Christie et al., 2023a*).



**Figure 2: Cultural, social and pathologic factors summarised as they impact breast cancer incidence and survival among Indigenous women in Australia.**

The impact of these factors on later presentation, more advanced disease at presentation, poorer compliance with screening, diagnosis and treatment, and poor outcomes are represented. Potential solutions to improve survival and disease incidence by focussing on behaviours and attitudes, and modifiable risk factors respectively are also mapped.

### **Limitations**

The major limitation of this research is the reliance on previously published work. It is possible that key publications have missed the data collection approach and been omitted from the investigation. Much of the literature relates to data collected over previous years and may not reflect the immediate status. Despite these limitations, the investigation reflects the major barriers to Indigenous health equality and informs strategies to address inequality. A degree of caution needs to be exercised in transferring learnings to other cancers or other marginalised groups. While every effort has been made to objectively evaluate rich evidence supported by insights drawn from multiple congruent sources, there remains a general lack of empirical evidence to provide evidence-based conclusions.

### **Conclusion**

Cultural and spiritual beliefs of Indigenous women may not readily align even with person-centred healthcare reform, yet it is important that those beliefs are not displaced within the healthcare system. When data gaps and inaccuracies are corrected, Indigenous women have both higher incidence and higher mortality of breast cancer compared to non-Indigenous women. Poorer outcomes relate to Indigenous patients presenting with more advanced disease; a confluence of early presentation in young Indigenous women, delayed diagnosis, lack of uptake of screening, less compliance with treatment and a higher proportion of aggressive phenotypes. Cultural and socioeconomic behaviours are significant barriers that create disparities between Indigenous and non-Indigenous women's access to and engagement with breast cancer services. Inequalities among Indigenous breast cancer patients are largely associated with modifiable factors that can improve survival and reduce incidence. Correction of these modifiable factors need to address historical injury and institutionalised bias to provide culturally safe and accessible health services for Indigenous breast cancer patients.

**Note:** The terms “Indigenous”, “Indigenous Australians”, “Indigenous peoples”, “Indigenous women” and “Indigenous patients” are used respectfully in this manuscript to refer to Aboriginal and Torres Strait Islander peoples of Australia. Accordingly, “non-Indigenous” makes reference to those that do not identify as Aboriginal and Torres Strait Islander peoples.

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