

# Understanding informed decision making

A literature review, stocktake and stakeholder insights about Australian women's attitudes to participating in population-based breast screening

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#### **KEY TERMS**

BMI	Body mass index
BSTRG	Breast Screening Technical Reference Group
CALD	Culturally and linguistically diverse
DCIS	Ductal carcinoma in-situ
HRT	Hormone replacement therapy

#### **GUIDANCE ON HOW TO READ THIS REPORT**

This report presents the findings of a narrative literature review, stocktake of resources and stakeholder insights about Australian women's views on participating in population-based breast screening. It contains seven main parts:

- 1. The *Key Findings* section provides a summary of the findings from the three research inputs (literature review, stocktake and stakeholder insights).
- 2. *Parts 1, 2* and *3* introduce this work, its purpose and describe the research methodologies used.
- 3. *Part 4* describes the findings from the literature review, including findings from the published, peer-reviewed literature and grey material (including material identified by BreastScreen Australia stakeholders at- or post-interview).
- 4. *Part 5* outlines the findings of the stocktake of resources and the resources received from BreastScreen Australia stakeholders.
- 5. *Part 6* summarises and presents insights from interviews with BreastScreen Australia stakeholders.
- 6. *Part 7* provides a short gap analysis for consideration by the Australian Department of Health.

Annex A includes weblinks to the resources identified in the stocktake. Annex B includes the semi-structured interview questions discussed with BreastScreen stakeholders and Annex C summarises who we met with.

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#### **KEY FINDINGS**

#### Background

The BreastScreen Australia program detects the earliest signs of breast cancer in well, asymptomatic Australian women aged 50 to 74 years. All breast screening is completed using bilateral full-field digital mammography. The Department of Health (Australia) is currently updating the BreastScreen Australia program's position statement on breast density and screening. This update is usefully informed by better understanding what Australian women know about breast cancer risk factors (including breast density), the benefits of and risks associated with participating in breast screening programs, and their attitudes towards and perceptions of screening. Understanding the ways in which women prefer to be communicated with and how knowledge, attitudes and perception influences engagement in screening is also important. Communicating some of these complexities is challenging. It is important to consider how best to provide women with the information they need and want in order to make an informed decision about participation in breast screening.

#### **Purpose of this work**

The Department of Health (Australia) contracted *Allen + Clarke* to undertake a literature review and stakeholder interviews investigating how women make informed decisions about participating in breast screening. *Allen + Clarke* were also contracted to undertake a stocktake of materials that Australian women might use to inform themselves of the benefits and risks of participating in population-based breast screening. The research questions were:

- What do women know and understand about the risks of breast cancer, and the benefits, risks and limitations of participating in breast screening?
- What are women's attitudes towards and perceptions of the risks of breast cancer, and the benefits, risks and limitations of participating in breast screening?
- How would women like to be informed about the risks of breast cancer, and the benefits, risks and limitations of participating in breast screening?
- What is the relationship between women's understanding, attitude and perceptions of the risks of breast cancer, and the benefits, risks and limitations of participating in breast screening and their participation in population-based breast screening?

#### Methodology

#### Literature review

*Allen + Clarke* completed a systematic search of the OVID Medline, Embase, ProQuest and SCOPUS databases as well as searches of Cochrane and clinical trials databases covering a date range of 1 January 2008 and 30 November 2018. We used combinations of subject/index terms as appropriate to the search functionality of each database. Articles were included if they met pre-determined criteria.

We found 54 relevant articles including eight systematic reviews, five narrative literature reviews, one randomized controlled trial, 32 observational studies and eight pieces of relevant grey literature. Primary studies already incorporated into systematic or narrative literature reviews were not further assessed unless additional material not described in the review was

included. Given the intended use of this work is to inform the BreastScreen Australia program about women's knowledge, attitudes and perceptions, we identified and included only studies that related directly to Australian women.

Within the parameters of this literature review, the evidence base on informed decision-making for breast screening among Australian women is limited, and mostly relates to population subgroups of Australian women (although many populations are not represented in the literature). Additionally, there is limited evidence on how women want to be informed about breast cancer risk and the risks and benefits of breast screening. That said, there is much that we do know.

#### Stocktake

For the stocktake, *Allen + Clarke* identified 36 main websites that are likely to be used by Australian women who might be looking for information about breast screening. We searched through these websites to identify resources that women might use (i.e., those with a consumer focus). We acknowledge that women are likely to not only look at Australian websites when searching for information about breast cancer risk and screening.

#### Interviews

We met with BreastScreen Australia stakeholders to discuss their insights into the research questions. Interviews took place in each jurisdiction in September 2019.

# What does the literature tell us about women's knowledge and understanding of breast cancer risk factors and screening?

We know a little about Australian women's knowledge, understanding and awareness of the risk of breast cancer and attitudes. We know more about their perceptions of breast cancer.

# Women know breast cancer exists but its relation to them personally is imbued with myths

Evidence from older grey literature indicates that Australian women have a good understanding of the prevalence of breast cancer; however, this understanding is imbued with myths, misunderstanding and fears. Common themes were that:

- breast cancer is symptomatic when detected (rather than the asymptomatic cancers detected in a screening exam)
- silence surrounds around the disease, which can adversely influence women's understanding of the disease or that it could affect them, and
- beliefs such as fatalism/what will be underpin knowledge of and attitudes towards breast cancer (and screening).

#### We know a little about Australian women's knowledge about breast cancer risk

This literature review returned limited information about Australian women's knowledge about breast cancer risk factors (in general) or their knowledge about specific risk factors (including age, family history, breast density, etc.). Identified studies tended to focus on specific groups of women within Australian communities, namely Aboriginal and Torres Strait Islander women and CALD women. Few risk factors were explored. These studies reported fairly low knowledge of breast cancer risk, leading to poorer engagement in screening/preventive health care. The study about CALD women identified that age was a well-known risk factor; few other risk factors were explored. One qualitative participation study provided considerable information about specific risk factors:

- Age: women do not routinely correctly understand increasing age as a strong risk factor for breast cancer, which affects their ability to understand the age eligibility parameters for the Breast Screen Australia program.
- Family history is likely to be misunderstood in a number of ways: many women may perceive breast cancer as an inherited disease. Women with a family history are likely to overestimate the risk; women without a family history are likely to underestimate the risk of developing breast cancer. Women with a breast cancer diagnosis have a better understanding than those without. Women generally have a poor understanding of what is meant by a family history and do not link this to first-degree relatives only.
- Breast density: we did not identify literature describing Australian women's knowledge about breast density as a risk factor for breast cancer (but acknowledge that studies by Stone et al. are in publication), but a systematic review based in the United States recorded fairly low levels of knowledge about breast density. This is interesting as in many American states breast density notification is mandatory and an increase in knowledge would be expected. In Australia, it could be assumed that knowledge of breast density may be even lower because notification of density results is not completed in most BreastScreen Australia programs.
- Modifiable risk and protective factors: some women understand that there are modifiable risk and protective factors, especially HRT but there appears to be confusion about alcohol consumption. There are also myths about other risk factors especially radiation exposure, stress and injury to the breast.

#### But fear is a factor in women's perception of breast cancer

Fear and beliefs such as fatalism strongly pervade the literature and can influence women's perception of their risk of breast cancer; fear crosses many cultures and includes women at higher familial risk of breast cancer. Fear is a major influencer of perception of breast cancer risk and health-seeking behaviour. Fatalism is also an important perceptive framework underpinning women's understanding of risk. These elements (fear, fatalism) were identified in Australian studies investigating Aboriginal and Torres Strait Islander and CALD women's perceptions of breast cancer risk. Aboriginal and Torres Strait Islander women fear cancer, see cancer as a death sentence and as a 'White man's' disease'. CALD women also fear cancer and believed it is possible they will get breast cancer in the future. Chinese-Australian women also believed talking about cancer incites bad luck. Fear and beliefs (such as fatalism) are strong themes and can influence women's perception of their risk of breast cancer; this belief crosses many cultures and includes women at higher familial risk of breast cancer. Fear can lead to inaccurate assessments of breast cancer risk.

# Women perceive mammography-based screening programs as useful, life-saving, the best way to detect cancer and more beneficial than harmful

Women generally perceive mammography programs as useful, life-saving, the best way to detect cancer (and reduce the risk of dying from it) and that these programs are more beneficial than harmful. It is seen as a way to avoid regret (if cancer is diagnosed early) or as a reassurance that cancer is not present. It is possible that women who regularly participate in screening feel more favourably toward screening than those who are under-screened. While understanding that

breast-screening is life-saving, Australian women do not clearly understand mortality reduction, with most women overestimating this. There are implications for such positive attitudes towards breast screening as it is likely to result in an overestimation of benefit.

# Australian women's awareness of the possibility of harm varies: evidence also indicates that few women understand the sensitivity of mammography or the impact of overdiagnosis

While women may struggle to correctly identify the sensitivity and specificity of mammography (with both over and underestimates reported), most women included in studies did understand that mammography might not identify every cancer; however, we note that other findings focus on women's relief at receiving at 'all clear' result and women's confusion should an interval cancer be diagnosed. Similarly, women's understanding of false positive test results varied considerably in the research.

Overdiagnosis appears to be a poorly understood health concept and one that women may not necessarily associate with breast screening (especially given that Australian research indicates that women often do not consider investigation of a lesion with a final benign outcome as overdiagnosis; rather they are grateful for a comprehensive investigation and peace of mind. This lack of understanding may impact on informed decision-making, with the majority of women being surprised that overdiagnosis exists and wanting to be informed of the risk of overdiagnosis (and what this might mean to them especially in the context of over-treatment). Other women disagreed, believing that this does not matter if women's lives are saved.

Older and very limited evidence suggests few women are concerned about radiation associated with mammography.

#### Women's participation in breast screening

We understand why women choose to participate in population-based breast screening and why they do not. The relationship between women's understanding of and attitudes towards participation in breast screening appears to vary by different population groups in Australia. We also know that women fear different things and this fear can drive adherence to breast screening recommendations, or it can scare women away.

- From the available literature focused on Australian women, we understand that a lack of knowledge of cancer, fear and beliefs of fatalism and cancer being a death sentence contribute to lower participation of Aboriginal and Torres Strait Islander women in breast screening; however, recognition of a higher genetic predisposition to cancer and family history of cancer can motivate participation.
- While fear and fatalism were also identified as beliefs among Chinese-Australian, Indian-Australian, and African migrant women, participation in mammography is relatively high for these groups: in the literature we reviewed, there appeared to be no significant relationship between knowledge and attitudes to screening and participation in screening in any of these population groups.
- Participation in mammography is relatively high for CALD women: in the literature, knowledge barriers were not associated with screening participation. For this population group emotional barriers were a significant factor in screening participation.
- In contrast, among Russian-speaking Australian women, participation in mammography is low; they rely on health professionals to motivate them to participate in screening. For these women, previous experience of compulsory breast screening

without education of risk factors for cancer has a profound impact on future screening choices. From very limited information, for women faced with a higher risk of breast cancer, fear and fatalistic beliefs can lead to avoidance of mammography, but in this group, screening choices can also vary widely.

Other key factors include consideration of how risk perception can promote or discourage screening (from either a view that cancer is inevitable or that it will not happen; women's mindset when it comes to preventive health, or the provision of trusted advice (either from a health practitioner or friends/family). Social influences are an important component and impact on a woman's awareness of breast cancer and her participation in breast screening. There is some evidence that body image and level of comfort being touched by a stranger act as barriers to participation.

From the limited literature, providing education to women on breast cancer and breast screening can increase knowledge, reduce misperceptions about cancer and increase participation in mammography, but when information on overdiagnosis/over-treatment is included in information to women about breast screening, while screening attitudes remain largely positive, women's attitudes to participating in mammography can change, including choices to not participate.

#### Communications: what do women want?

We know very little about the range of information Australian women want to know or how they want to be informed about breast cancer risks and population-based breast screening. We do know that providing education to women on breast cancer, risk factors and breast screening can increase knowledge, reduce misperceptions about cancer and increase participation in population-based breast screening. We also learnt that many women want full, balanced information on screening, including issues associated with overdiagnosis/over-treatment but other women may be more concerned that changing the 'pro' screening message to include more balanced information could result in confusion. Key messages could potentially focus on describing:

- mammography as a test and how the procedure will be implemented
- breast cancer incidence and that breast screening saves lives through early detection and wider treatment options/choices
- risk factors and what is known (especially regarding increasing age and why screening is most appropriate for women aged over 50 years)
- including information about overdiagnosis/over-treatment but also acknowledging what we do not know (i.e., that screening finds some cancers that would never cause harm but we do not know which ones, so we treat everything and we are working to better identify non-harmful lesions), and
- present statistical data in icon arrays.

Importantly, all communications need to be delivered in a way that is culturally safe and competent. Aboriginal and Torres Strait Islander women want more information on breast cancer including its meaning and signs/symptoms to enable them to engage in screening, and that education delivered by local Aboriginal and Torres Strait Islander women who are well-regarded in the community and preferably who have personal experience of cancer would likely have an impact on screening participation.

Having a cascade of communications approaches and multiple touchpoints enables women to engage with content as they need, including simple overview messaging and more detailed evidence reviews. Ideally, this information is delivered by trusted advisors who have considered the reasons why women participate in screening (or do not) so that content can be more personalised to the woman reading it.

#### Stocktake: we know that there are a lot of resources to support women's understanding of breast cancer risk and the benefits of participating in breast screening, but there are some areas where finding detailed information about specific risk factors requires more effort

Our stocktake identified a large amount of consumer-focused resources. Information was widely available, easy to find, found on all websites we looked at, and plentiful: we identified a total of 227 resources from 36 websites. Most of the resources contained a moderate amount of detail delivered in short, simple messages. Fewer resources provided depth about particular issues.

It was particularly easy to find information about breast anatomy, breast cancer symptoms and breast cancer risk factors; however, the depth of information for individual breast cancer risk factors varied widely (for example, age could be discussed as 'increasing age' or in more detail such as providing more targeted information about the risk profile associated with increasing age). Information about breast density was variable with more websites discussing the masking effect of breast density on mammography and fewer discussing or clearly articulating the impact of breast density as an independent risk factor for breast cancer.

There was a lot of material promoting breast awareness (with messages focusing on knowing what is normal for an individual woman) and understanding the symptoms of breast cancer (beyond feeling a lump in the breast or armpit). Recommendations encouraging women to participate in organised, population-based screening programs were common, with the benefits of early detection strongly promoted. There was less information about the potential harms and limitations associated with breast screening in healthy women, although some sites did discuss overdiagnosis, over-treatment, the impact of a false positive and radiation dose.

Most resources did not appear to be written with a specific population group in mind but there were some resources developed for Aboriginal and Torres Strait Islander women and other resources were available in a range of languages. We know from interviews however that there are a lot of resources available in a range of languages.

# Interviews: we heard both new insights and views that confirm some of the finding of the literature review

Important contextual information influences our understanding of women's knowledge and beliefs about breast cancer, risk factors and screening. Much of this understanding is held in BreastScreen Australia state/territory programs, and we appreciate their engagement with us on this work. Key insights include that women are not a homogeneous group: there are many unique factors that underpin women's knowledge and their engagement with screening services. Often, research presents information about knowledge at a specific point in time for women who were involved in screening at that time (and who may no longer be): this has implications for the applicability of older research to contemporary settings. Another key contextual factor is that research needs to be clear about whether participants are regular screeners or are underscreened (including never-screeners) as women engaged in screening are likely to hold more positive views about screening than those who do not participate regularly. Encouraging a culture of co-design and engaging women to ask what they want to know and how are also fundamental to effective communications and ensuring informed decision-making. Interview participants told us that many things that reflect the findings of the literature review, as well as some new insights. Key findings included that women have a good understanding of breast cancer but there is variation with key limits relating the cancer as a diverse suite of diseases. Women's understanding of risk factors varies across and between cohorts of women, with some overstating and others underestimating specific risk factors, with knowledge underpinned by the following:

- women who have had some personal experience of breast cancer (either themselves or a friend/family member) are often better informed
- being female and increasing age are known as risk factors but are often poorly understood, especially risk for women aged in their 40s (often a perception of a higher risk) and for women aged over 75 years, which creates confusion for women about when to start and stop screening
- family history as a risk factor is well-known (but it is not well understood) and often over-estimated with limited understanding of what a family history means
- breast density as a risk factor is not well-understood, is an emerging issue for some jurisdictions but not others but regardless of this, requires increased consensus on management and notification to reduce confusion and ensure confidence in the BreastScreen Australia program, and
- overall, risk is a challenging concept to communicate well but there are ways that it can be communicated (eg, icon arrays, multi-level and layered information).

Other insights included that women and health practitioners may not understand the difference between screening mammography and diagnostic mammography, or this may reflect service delivery choices/prioritisation, and that the benefits of screening are well-understood but limitations may not be (and while there is awareness of overdiagnosis/over-treatment, more information is needed), and care is needed to communicate balanced advice about benefits and harms with the risk of doing harm if a women does not screen and the need to achieve participation rates. We heard that supporting informed decision-making requires continuous effort across multiple service touchpoints and managing implied consent requires skill.

Interview participants also noted that each communications strategy works at least some of the time for some women but that a successful approach needs to involve multi-layered, multi-focal approaches across the whole of a woman's screening journey (i.e., providing for care, concern and dignity from her first screen to her last screen). It is also very important to pay attention to delivering content in a way that is culturally safe and competent and in a way that recognises different life stages may require different information. Information also needs to consider the needs of health practitioners as well.

Interview participants also identified a small number of research gaps and communications needs, including the need for research about breast cancer incidence in different populations and ways to manage overdiagnosis.

#### Gap analysis: advice on communications

There is a good understanding of how to communicate with women (in general). Offering layered, relatable information that resonates with a woman's overall approach to preventive health in a wide range of formats/places where women are looking, and providing this information often given that the cohort of women eligible for and participating in breast-screening changes all the time. As noted by interview participants, every communication strategy works for some women, some of the time: multiple touchpoints and cascades of information are key. Some research has been completed which looks to segment the barriers to screening experienced by under-screened women: this research also offers some further potential areas in which to focus communications if the intention is to increase screening participation. There are of course significant implementation costs and considerations associated with developing and running multi-focal, multi-layered communications campaigns. There may be further opportunities for programs/federal agencies to share in the development and implementation of such activities or to refine existing approaches and roll-out across all programs.

An area consistently identified as challenging by stakeholders was communicating complex clinical information when the science may not provide settled evidence on the direction to take or when there is no clear consensus on what to do. This is problematic for both women who are deciding on whether to participate in breast-screening as well as clinical staff who are providing advice. Key areas where further consensus would be useful are how best to communicate risk in a way that resonates with women, the role of breast density (both as a risk factor for breast cancer and its role in decreasing the sensitivity of mammography), and potential harms associated with over-treatment of detected lesions. No clear consensus on the information that could/should be provided (and by whom) was provided through either the literature review or the stakeholder interviews. However, it is also clear that trusted health advisors (including GPs) also probably require further information about the benefits, harms and limitations of breast-screening in order for them to support women's informed decision-making.

#### 1. Background

In 2017, the Department of Health and Ageing (Australia) commissioned *Allen + Clarke* to complete a literature review on breast density and mammography<sup>1</sup> to inform an update to BreastScreen Australia's position statement on breast density and screening. This literature review asked questions about the advice and support that women wanted and needed about breast density if it was to be reported. It did not seek research on Australian women's current level of knowledge about breast density as an independent risk factor for breast cancer, or their understanding of other risk/protective factors for breast cancer.

*Allen + Clarke*'s literature review noted that women and health professionals must be informed of the meaning of the information in any breast density notification, including breast density's role as a risk factor, its masking effect when using mammography, what breast density reporting means for clinical practice and how it could influence a woman's approach to participation in population-based breast screening. Advice about breast density is an example of information that some women may want in order to make an informed decision about their participation in screening.

The Department of Health's Breast Screening Technical Reference Group (BSTRG) considered *Allen + Clarke*'s literature review on breast density at its meetings in March 2018 and August 2018 and acknowledged the complexities of communicating complex clinical information about breast density. The BSTRG also noted that the literature review (and any updates to the breast density position statement) was limited by uncertainty about how best to communicate information about risk so as to provide evidence-based advice about breast density to women in a way that supports informed decision-making. Following the BSTRG's advice in August 2018, the Department of Health and Ageing (Australia) commissioned *Allen + Clarke Policy and Regulatory Specialists Limited (Allen + Clarke*) to:

- complete a literature review of published, peer-reviewed Australian literature exploring informed decision-making about participating in population-based breast screening, including considering Australian women's knowledge, attitudes and beliefs about breast cancer risks and the benefits and harms of participating in screening and how this might influence intention to screen as well as screening choices, and
- undertake a stocktake looking at materials that Australian women might use to inform themselves of the benefits and risks of participating in breast screening.

A draft report was prepared by *Allen + Clarke* and presented to the BSTRG in April 2019. Key recommendations from the BSTRG included:

- increasing the scope to include Australian grey literature, including seeking information about women's knowledge, perceptions, attitudes and beliefs from state/territory BreastScreen programs (as the experts in communicating with women about screening)
- providing more research on the impact of family history on screening participation by expanding the jurisdictions covered to include published, peer-reviewed literature from Canada, the USA and the United Kingdom if it can be generalized to the Australian population, and

<sup>&</sup>lt;sup>1</sup>Breast Density: A literature review to inform BreastScreen Australia's position on breast density and screening. Final report, 10 September 2018. *Allen* + *Clarke Ltd* 

• (if possible), providing a gap analysis framework about what is known for communicating to sub-populations and what women know/do not know.

#### 2. Purpose of this Report

This report is an omnibus update of *Allen + Clarke's* initial report on informed decision-making. It has been prepared in line with the recommendations made by the BSTRG at its April 2019 meeting. This report articulates what we know (and do not) about Australian women's knowledge and understanding of and perceptions about breast cancer risk/protective factors, the benefits and risks of participating in population-based screening (including women's knowledge of overdiagnosis), how this knowledge influences intention to screen and participation in screening, and Australian women's communication needs and preferences. Information is drawn from:

- published, peer-reviewed Australian research, and robust published, peer-reviewed research from Canada, the USA and the United Kingdom (where it is applicable to Australian women)
- grey literature about Australian women's knowledge, perceptions, attitudes about breast cancer risk and screening as prepared by or sourced from reputable Australian organisations including BreastScreen Australia state/territory programs
- Australian resources available to support women's understanding, including resources identified from a desk-based review completed by *Allen + Clarke* in early 2019, and conversations with BreastScreen state/territory programs to ensure the full range of available resources is captured (including material in development)
- insights provided from BreastScreen Australia state/territory program stakeholders, and
- gap analysis, including insights into possible areas for further consideration.

#### 3. Methodology

#### Summary

- This report provides an overview of Australian women's knowledge, understanding, attitudes towards and perceptions of breast cancer risk and the benefits and harms associated with breast screening, and how this might influence participation in breast screening.
- The literature review component is not a systematic review. We have provided information about the methodology of the published, peer-reviewed studies included in this review. No primary research or pooled analysis was undertaken. The following databases were searched in November 2018: EMBASE, OVID Medline, CINAHL, ProQuest and SCOPUS. The following websites were reviewed: clinicaltrials.gov, the Cochrane database, NICE, INAHTA, and the UK NHSBPS. We expanded the literature search in August 2019 to include studies published in the Canada, the USA and the United Kingdom which had some generalisability to Australian women (as per the advice of the BSTRG). All returned citations and abstracts were assessed for relevance to the research questions, to the Australian context and the overall inclusion criteria. The same criteria were used to review the full-text and bibliographies of all articles proposed for inclusion. A total of 46 published, peer-reviewed articles met the inclusion criteria, and are discussed in this review.
- Grey literature was identified on agreed Australian websites and provided by BreastScreen Australia stakeholders during or following interviews with the *Allen* + *Clarke* project team. Some grey material provided by BreastScreen stakeholders can only be referenced obliquely due to the nature of the research and the purposes for which the material was originally collected. A total of eight items were included in this document. Eight pieces of grey literature were included.
- We interviewed stakeholders from all BreastScreen Australia programs, except for BreastScreen ACT. Each interview used a semi-structured approach and sought to identify insights about Australian women's understanding of breast cancer risk factors, the benefits and harms of screening, resources and gaps. We are grateful for the time BreastScreen stakeholders spent with us, and for freely sharing their insights and grey literature about women's understanding.
- The findings and any conclusions of the literature review drawn need to be considered in light of the broad range of methodologies used in the research, which create challenges for comparison and synthesis. The evidence base on Australian women's understanding of breast cancer risk/protective factors and breast screening is limited but there was a good degree of consensus between the qualitative research and feedback provided to the project team at interview. We have used this information to complete the gap analysis.

#### 3.1. Objectives

This research focuses on breast screening only.

It draws on three sources of information:

1. A review of published peer-reviewed literature and grey material

- 2. A stocktake of publicly available resources, and
- 3. Interviews with BreastScreen Australia programs and stakeholders.

Each stream focused on informed decision-making and women's attitudes towards participating in population-based breast screening programs.

Firstly, we explored published social research and grey literature (including surveys and qualitative research in psychological, sociological and health communication literature) about women's understanding of, attitude to and communication preference for information about:

- Breast cancer risk both as a general risk and individualized risk
- Benefits and risks of participating in a breast screening program (eg, overdiagnosis, over-treatment, false positives, etc.)
- Limitations of breast screening programs
- Women's communication needs and preferences, and
- Other factors that may influence women's decision to participate.

To enable the results of the literature review to be interpreted within the context of BreastScreen Australia, we undertook a stocktake of publicly available material produced in Australia (either by BreastScreen Australia, BreastScreen state/territory programs, breast cancer networks/foundations, health professional bodies, or other groups), which described the benefits and risks of participating in breast screening.

In recognition of expertise held in BreastScreen Australia state/territory programs, we then met with BreastScreen Australia state/territory stakeholders to capture the collective their expertise/insights about how best to communicate with women about breast cancer risks, and screening benefits and risks (including insights about communicating with different population groups), and to identify any grey literature held or developed by BreastScreen Australia programs about women's knowledge and understanding of breast cancer risk factors and the benefits and risks of participating in breast screening (for inclusion in the literature review).

#### 3.2. Review of published, peer-reviewed and grey literature

#### 3.2.1. Research questions

This literature review explored four questions. All questions focus on Australian women's understanding and attitudes (rather than attitudes from women living in other countries); however, with the BSTRG's advice, we expanded the inclusion criteria to include large reviews and studies from Canada, the USA and the United Kingdom that might be generalisable to Australian women.

#### **Question 1**

What do women know and understand about the:

- risk of breast cancer (individual risk and general population risk)?
- benefits, risks and limitations associated with participation in an organized breast screening program?

#### **Question 2**

What are women's attitudes towards and perceptions of the:

- risk of breast cancer (individual risk and general population risk)?
- benefits and risks associated with participation in an organized breast screening program?

#### **Question 3**

How would women like to be informed about the risk of breast cancer and the benefits and risks associated with participation in an organized breast screening program?

#### **Question 4**

What is the relationship between women's understanding of risk of breast cancer and the benefits and risks associated with participation in an organized breast screening program and their participation in an organized breast screening program?

SUPPLEMENTARY QUESTION: How do women's knowledge/beliefs/attitudes to participation in organized breast screening change in response to information about risk of breast cancer and the benefits, limitations and risks associated with participation in a screening program?

#### 3.2.2. Literature searches

#### **Primary search**

The following databases were searched in November and December 2018:

- CINAHL
- Cochrane Library database
- National Institute for Health and Clinical Excellence
- OVID (including Embase, Medline and PsychINFO)
- ProQuest, and
- SCOPUS.

To complete a systematic search, we used combinations of subject/index terms where appropriate (eg, exploded term 'mammography') in combination with key words, or key words alone depending on the search functionality of each database or website (eg, main searches included 'attitude' PLUS 'breast cancer' PLUS 'Australia\*' OR 'know\*' in the title or abstract).

The following limits were applied on all searches:

- a date criterion (1 January 2008 30 November 2018)
- full English language manuscripts/articles, and
- study type restrictions (where available and appropriate, we restricted returns from research databases to peer-reviewed systematic reviews, literature reviews, RCT, observational studies and clinical trials).

Duplicate citations and a small number of false hits/inaccurate returns were removed before all initial returned citations and abstracts were reviewed for relevance to the main research questions. Material was excluded if it:

- did not relate to women's knowledge about population-based breast screening (i.e., the article may have focused on understanding of a breast cancer treatment pathway or related to health professionals' communications with women about breast screening)
- did not clearly relate to Australian women's understanding, attitudes or knowledge
- focused on testing a decision aid or content about overdiagnosis as an issue (without information on Australian women's understanding, attitudes or knowledge), and
- described a study protocol or validation of a questionnaire or tool without information about Australian women's baseline knowledge.

To determine if this first search retrieved the correct range of available research, a validation process was completed using a recent systematic review relevant to the primary research questions (Seaman et al., 2018). There was a lower than expected consistency between the studies returned using our strategies and those included in the Seaman et al., review, so we completed a search sweep of studies, which resulted in a greater consistency.

From this first sweep, full texts for all proposed inclusions were retrieved and reviewed for relevance to the research questions and inclusion criteria. An appraisal of study design (to determine overall quality) was completed and the bibliography of each included article was reviewed to identify other relevant research that may be of interest.

Study types were six systematic reviews, two narrative literature reviews, one randomized controlled trial, and 19 articles.

#### **Supplementary search**

Following advice from the BSTRG, we expanded the literature search to include more research on the impact of family history and screening participation, and key international literature about communicating with women about participating in breast screening and/or breast cancer risk factors from Canada, the USA and the United Kingdom if it could be generalisable to the Australian population. Using the same research questions (articulated in *section 4.2.1*), we searched OVID Medline, the National Institute of Clinical Excellence and the Cochrane database for relevant published, peer-reviewed evidence. Inclusion criteria included a date criterion (1 January 2008 – 30 November 2018), full English language manuscripts/articles, and study type restrictions (where available and appropriate, we restricted returns from research databases to peer-reviewed systematic reviews, literature reviews, RCT, observational studies and clinical trials). We also reviewed the list of citations returned in the primary search to identify any systematic reviews, narrative reviews or robust primary studies undertaken in Canada, the USA or the United Kingdom, which might have been excluded in the initial review (which did not extend to papers with a study population not based in Australia).

We also undertook a search of the following websites to identify grey material published by organisations with an interest in breast screening in Australia. These websites included:

- Australian Clinical Practice Guidelines
- Australian Institute of Health and Welfare
- Breast Cancer Network Australia
- BreastScreen Australia (federal and all state/territory websites)
- Cancer Australia (national and all state/territory websites)
- Cancer Councils (all states and territories)
- Department of Health (federal and state/territory departments)
- InformD
- McGrath Foundation
- National Breast Cancer Foundation
- Pink Hope Australia, and
- Public Health Association of Australia.

The supplementary search for grey literature was also supplemented by the provision of internal reports identified by BreastScreen stakeholders during interviews (see *section 4.4*).

Final numbers and the included study types across both the primary and supplementary searches were:

- eight systematic reviews (including a Cochrane review on personalized risk communications and informed decision making in a screening setting)
- five narrative literature reviews
- one randomized controlled trial
- 32 primary studies (either prospective or retrospective observational studies), and
- eight grey literature publications.

#### 3.3. Stocktake

*Allen + Clarke* conducted a desk-based resource scan to identify the existing range of information available to women about breast cancer, breast density and screening, and participation in population-based breast screening programs. This will help to explain how Australian women are informed about breast cancer and breast screening.

#### 3.3.1. Breadth of website search (Australian websites only)

Our initial stocktake covered a list of 36 Australian-based websites. It focused on consumeroriented webpage content, brochures, pamphlets and videos of relevance to the primary research questions. We also referred to other Australian websites where they were crossreferenced from one of the websites in our initial list and included any resources that met the criteria. The full list of websites is:

- Australasian Menopause Society (*No resources were collected from this website as available material focused on study releases or news article rather than original content*)
- Australian Indigenous HealthInfoNet (*No resources were identified on this website*)
- Breast Cancer Network Australia
- BreastScreen Australia (national and state/territory websites)
- Cancer Australia
- Cancer Council Australia (national and state/territory websites)
- Healthdirect.gov.au
- InformD
- McGrath Foundation
- MyDr.com.au
- National Breast Cancer Foundation
- New South Wales Centre for Genetics
- Pink Hope and Be Dense Aware
- State/territory government agency health information pages
- Virtual Medical Centre (myVMC.com), and
- Westmead Breast Cancer Institute.

#### **Inclusions and exclusions**

From the results of the stocktake, resources will be prioritized according to the following criteria:

• Consumer-focused webpage content, brochures, pamphlets, posters published by credible organisations

We recognise that information and advice provided in chat forums/online groups may be useful to women. There are many such websites (including peer-peer forums and those in which health professionals engage) based both in Australia and abroad. Information provided on these websites may come from credible sources, but we will not search these due to the difficulty in confirming credibility.

- Currency (i.e., available on the website on the day of the search)
- Relevance to primary research questions, and
- Available in English language (resources in other languages will be noted).

Specific exclusions were information focused only on cancer prevention and recurrence prevention, including recommendations to reduce modifiable risk factors, information about men and their risk of breast cancer (not eligible for participation in the BreastScreen Australia program), archived or non-current resources, information from private radiology practice websites, risk assessment tools/advice, and blog posts and media releases (including published studies and clinical trials).

The stocktake resources were recorded in a table (see *Annex A*). Information relating to the subject area, format, comprehensiveness, and any other notable information was recorded.

#### 3.4. BreastScreen Australia stakeholder interviews

The purpose of the BreastScreen Australia stakeholder interviews was to hear insights and advice about Australian women's understanding of breast cancer risk factors and the benefits and risks of participating in screening for those delivering screening services to women. We asked about:

- interview participants' insights into women's understanding of or awareness of reports or data about Australian women's knowledge of and attitude or perceptions towards breast cancer risk and the benefits and risks of breast screening (including any research or papers that organisations may have commissioned or completed on this topic as part of campaign or resource development)
- any resources used to support women's understanding of breast cancer risk factors and the benefits and risks of participating in screening (including commenting on the list of resources identified by *Allen + Clarke* in the stocktake see *section 4.3*)
- advice, insights and research into how best to effectively influence women's understanding of breast cancer risk factors and the benefits and risks of participating in screening, and women's resource/communications needs, and
- advice on gaps in the information women receive and/or recommendations to address any issues or concerns raised.

*Allen + Clarke* initially approached stakeholders by email to invite them to participate in an interview. We provided information about the purpose, background and intended output of the interview, anticipated time commitment, preferred method of engagement (face-to-face at their workplace or tele-interview), consent requirements, and confidentiality. If stakeholders agreed to participate, a time convenient to them in September 2019 was organised.

We met representatives from all BreastScreen state/territory programs except BreastScreen ACT.

#### 3.4.1. Consent

Completed consent forms were collected by *Allen + Clarke* interviewers at each interview.

#### 3.4.2. Interview structure

Interviews were semi-structured. The interview guide was agreed with the Department of Health to ensure the discussions covered the breadth of issues required and were relevant to participants' knowledge and experience. This approach allowed discussions to develop and issues to be explored in depth. A copy of the interview guide is included in *Annex B*. Interviews took up to three hours. Two *Allen + Clarke* interviewers were present at each interview. Interviews were not audio-recorded, but detailed written notes were taken.

#### 3.4.3. Qualitative analysis

Findings from each interview were written up and analyzed to identify themes and areas of agreement and difference in opinion across all of the participants. We have presented content

thematically and have not linked or attributed comments to interview participants without their permission.

#### 3.5. Interpretation

The findings presented in this report need to be considered in light of the following limitations, which created challenges for comparison and synthesis.

Specific information about the development and use of educational programs/decision-making tools/aids was not included in our terms of reference but is covered in research underway with the New South Wales Cancer Council; however, we included findings from studies using decision aids and education programs where these contained information about Australian women's baseline knowledge, understanding, attitudes to and perceptions about breast cancer, breast screening and the benefits and risks of participating in organized breast screening programs.

Published literature included a broad range of methodologies, including systematic reviews, randomized controlled trials, narrative literature overviews, qualitative studies, pilot educational studies, and descriptive survey reports. Many papers did not specifically consider Australian women's knowledge, understanding, attitudes or perceptions (although there is a body of evidence about what women in other countries know and understand); however, we did identify a number of papers about Australian women's knowledge). Observational studies focused on specific sub-populations of Australian women including Aboriginal and Torres Strait Islander women, Chinese-Australian women, Indian-Australian women, African migrant women, CALD women and women who were at higher familial risk of breast cancer: we did not identify any papers that focused on broader population groups (however, there is information contained in grey literature commissioned by BreastScreen Australia state/territory programs). Study authors generally noted generalisability limitations (including to the general population as well as other women in the same population group within Australia who may have different demographic characteristics).

We also note that studies seeking to identify women's knowledge, understanding and attitudes are necessarily 'point in time' in nature; they reflect the 'women that were'. This means women's knowledge and preferences today (and tomorrow) may differ, especially as the ways that women receive and digest information (particularly in the digital environment) is changing rapidly.

Ethical, legal or social issues associated with participation in population-based breast screening programs (or choosing not to) were specifically excluded from our work.

A systematic review with pooled analysis has not been performed.

While outside of the inclusion date range, we included a participation qualitative study by Blue Moon Research & Planning (2008). This was included because it is one of the few comprehensive pieces of research about Australian women's understanding of the BreastScreen Australia program, particularly their understanding of the benefits and risks of participating in screening. The importance of including this research was stressed by several interview participants and the Department, given its scope and relevance to our questions. Also, a number of grey literature papers were presented to us in (or post-) the interviews with BreastScreen Australia stakeholders. These generally focused on understanding women's motivations to screen or under-screened women's reasons for lower participation in screening. We have included these studies where we had permission to do so and note that there were some studies for which we did not have permission to cite. That said, the insights offered through these studies was similar to the insights included in published material and we are confident that this report does capture most of the main findings.

A number of limitations also apply to the stocktake. Due to the number of resources available worldwide, we did not collect resources from websites outside of Australia. Where websites provided links to credible organisations based in other countries, these were noted but not reviewed. There are many websites (including blogs, social media, and peer-peer forums) based both in Australia and abroad which women may use to seek information or advice about breast cancer and screening. Information provided on these websites may come from credible sources (including health professionals). We do not know where Australian women choose to access their information from, how many people have accessed the resources or what women's knowledge and understanding is of the information provided in the resources.

We also note that women are not a homogeneous group, so care is needed in extrapolation.

#### 4. What do Women know about Breast Cancer, risk factors and screening and how does this affect their decisions to participate in screening: literature review findings

"Best practice ensures that women who participate in the BreastScreen Australia Program are fully informed about breast cancer screening, including the likely benefits and possible harms, as well as any risks or uncertainties related to the screening process. The information provided will need to be sufficient to enable women to give their informed consent to participate in screening and to undergo any assessment investigations that may be required". National Accreditation Standards (BreastScreen Australia Accreditation Review Committee, 2019).

*Part 4* of this report describes the findings of the literature review on published, peer-reviewed evidence about Australian women's knowledge of breast cancer and screening, and findings on the same topics identified in grey literature. It contains five sections about Australian women's:

- 1. knowledge, understanding and perceptions of breast cancer and risk factors
- 2. knowledge and awareness of and attitudes towards population-based breast screening
- 3. understanding of the risks and benefits of participating in population-based breast screening
- 4. relationship between their understanding of and attitudes to breast screening and their intention to or participation in screening, and
- 5. preferences about being informed of the risk of breast cancer and the benefits and risks associated with participation in a population-based screening program.

# 4.1. Australian women's knowledge, understanding and perceptions of breast cancer and risk factors

*Section 4.1* of this report describes the findings presented in published, peer-reviewed literature and grey literature for research question 1:

What do women know and understand about the risk of breast cancer (individual risk and general population risk) and the benefits, risks and limitations associated with participation in an organized breast screening program?

Information presented in *section 4.1* specifically focuses on women's understanding about the breast cancer and their understanding of specific risk and protective factors (insofar as these are described in the literature: we did not identify literature relating to a number of known risk factors). Information about knowledge of population-based breast screening and the benefits and risks associated with participation in screening are described in *section 4.2* and *section 4.3* respectively. Published studies were generally small, qualitative studies about Aboriginal and Torres Strait Islander and CALD women's understanding of breast cancer. The papers discussed in this section of the literature review are listed below and overleaf.

#### Systematic reviews

Two systematic reviews: Santiago-Rivas et al., 2016; Ackerson & Preston, 2009.

#### Literature reviews

One review: Shahid & Thompson, 2009.

#### **Observational studies**

11 observational studies: McBride et al., 2019; Glassey et al., 2018; Pilkington et al., 2017; Cullerton et al., 2016; Fehniger et al., 2014; Thompson et al., 2014; Treolar et al., 2013; Kwok et al., 2012; Keogh et al., 2011; Kwok et al., 2011; Katapodi et a., 2009; Shahid et al., 2009

#### **Grey literature**

Four papers: BCNA, 2018; Open Mind 2012; Essence, 2011; Blue Moon Research & Planning, 2008.

#### **Key findings**

#### Women know breast cancer exists but its relation to them personally is imbued with myths

Evidence from older grey literature indicates that Australian women have a good understanding of the prevalence of breast cancer; however, this understanding is imbued with myths, misunderstanding and fears. Common themes were that:

• breast cancer is symptomatic when detected (rather than the asymptomatic cancers detected in a screening exam)

• silence surrounds around the disease, which can adversely influence women's understanding of the disease or that it could affect them, and

• beliefs such as fatalism/what will be underpin knowledge of and attitudes towards breast cancer (and screening).

#### We know a little about Australian women's knowledge about breast cancer risk

This literature review returned limited information about Australian women's knowledge about breast cancer risk factors (in general) or their knowledge about specific risk factors (including age, family history, breast density, etc.). Identified studies tended to focus on specific groups of women within Australian communities, namely Aboriginal and Torres Strait Islander women and CALD women. Few risk factors were explored. These studies reported fairly low knowledge of breast cancer risk, leading to poorer engagement in screening/preventive health care. The study about CALD women identified that age was a well-known risk factor; few other risk factors were explored. One qualitative participation study provided considerable information about specific risk factors:

• Age: women do not routinely correctly understand increasing age as a strong risk factor for breast cancer, which affects their ability to understand the age eligibility parameters for the Breast Screen Australia program.

• Family history is likely to be misunderstood in a number of ways: many women may perceive breast cancer as an inherited disease. Women with a family history are likely to overestimate the risk; women without a family history are likely to underestimate the risk of developing breast cancer. Women with a breast cancer diagnosis have a better understanding than those without. Women generally have a poor understanding of what it meant by a family history and do not link this to first-degree relatives only.

• Breast density: we did not identify literature describing Australian women's knowledge about breast density as a risk factor for breast cancer (but acknowledge that studies by Stone et al. are in publication), but a systematic review based in the United States recorded fairly low levels of knowledge about breast density. This is interesting as in many states breast density

notification is mandatory and an increase in knowledge would be expected. In Australia, it could be assumed that knowledge of breast density may be even lower because notification of density results is not completed in most BreastScreen Australia programs.

• Modifiable risk and protective factors: some women understand that there are modifiable risk and protective factors, especially HRT but there appears to be confusion about alcohol consumption. There are also myths about other risk factors especially radiation exposure, stress and injury to the breast.

Some international literature also indicates that women are generally poor at assessing the risk of breast cancer and applying it to themselves.

#### But fear is a factor in women's perception of breast cancer

Fear and beliefs such as fatalism strongly pervade the literature and can influence women's perception of their risk of breast cancer; fear crosses many cultures and includes women at higher familial risk of breast cancer. Fear is a major influencer of perception of breast cancer risk and health-seeking behaviour. Fatalism is also an important perceptive framework underpinning women's understanding of risk. These elements (fear, fatalism) were identified in Australian studies investigating Aboriginal and Torres Strait Islander and CALD women's perceptions of breast cancer risk. Aboriginal and Torres Strait Islander women fear cancer, see cancer as a death sentence and as a 'White man's' disease'. CALD women also fear cancer and believed it is possible they will get breast cancer in the future. Chinese-Australian women also believed talking about cancer incites bad luck. Fear and beliefs (such as fatalism) are strong themes and can influence women's perception of their risk of breast cancer; this belief crosses many cultures and includes women at higher familial risk of breast cancer. Fear can lead to inaccurate assessments of breast cancer risk.

#### 4.1.1. Awareness of breast cancer is high

Blue Moon Research & Planning undertook a participation qualitative study (Blue Moon Research & Planning, 2008) to understand Australian women's perceptions about the availability, accessibility and acceptability of the BreastScreen Australia program. Several of the research areas<sup>2</sup> have a strong applicability to *Allen + Clarke*'s research project and so we have included information from this study throughout the literature review (even though the paper falls outside of our included date range). To complete their research, Blue Moon Research & Planning undertook 32 focus groups and 16 in-depth interviews with women aged over 40 years from metropolitan and rural areas in all Australian jurisdictions, inclusive of Aboriginal and Torres Strait Islander peoples and CALD women and women with disabilities, and inclusive of women who are have had a range of engagements with the BreastScreen Australia program (i.e., regular screeners, those who are lapsed screeners and those who have never screened; women recalled to assessment with a final benign outcome or a cancer diagnosis, and women with a diagnosed interval cancer). The researchers also interviewed health professionals (including GPs, Aboriginal and Torres Strait Islander health workers, breast physicians, and nurse counsellors). A final total number of participants was not articulated in the monograph.

Overall, awareness of the prevalence of breast cancer was high among Blue Moon study participants.

# **4.1.2.** Understanding of and knowledge about breast cancer varies and is imbued with myths, misunderstandings and fears about mortality

Common themes were that:

- breast cancer is symptomatic when detected (rather than the asymptomatic cancers detected in a screening exam)
- silence surrounds around the disease, which can adversely influence women's understanding of the disease or that it could affect them, and
- beliefs such as fatalism/what will be underpin knowledge of and attitudes towards breast cancer (and screening).

We identified one international study (Fehniger et al., 2014) which explored questions about women's ability to correctly contextualise risk to their own situation (a complex and challenging task requiring considerable health literacy). Fehniger et al. collected baseline information on risk perception and concern about breast cancer as part of BreastCARE, a randomized controlled trial designed to evaluate a PC-tablet based intervention that provides multi-ethnic women and their primary care physicians with tailored information about breast cancer. Twenty five percent of the 1,261 participants, were classified as high risk of developing breast cancer. The authors reported that among average-risk women, the majority (72%) correctly perceived themselves to be average or lower than average risk for breast cancer compared to other women their age. However, only 18% of high-risk women were reported to have correctly perceived themselves to be at increased risk. The authors found that age was a statistically significant predictor of correct risk perception among average and high-risk women. Average risk women aged under 65 years had significantly lower odds of correctly perceiving their breast cancer risk, compared with women over 65 years; however, high risk women under 65 years were significantly more likely to correctly perceive their breast cancer risk compared with women

 $<sup>^2</sup>$  Namely seeking information from women about the factors that discourage participation in the program, the impact that communications activities have on participation (including the impact that communications have on informed choice), and women's understanding of the benefits and risks associated with participating.

aged over 65 years. For average risk women with four or more comorbidities and a family history of breast cancer had a lower odds of correctly perceiving their breast cancer risk compared with average risk women with 0-1 comorbidities and no family history of breast cancer. The authors also reported that average risk women with correct perception of breast cancer risk had lower odds of concern about breast cancer than those with an incorrect perception of risk, whereas among high risk women who correctly perceived their breast cancer risk, the odds of breast cancer concern was five times higher than high risk women who incorrectly perceived their risk.

#### No symptoms = no cancer

A key myth mentioned in a number of papers (including Pilkington et al., 2017, Kwok et al., 2011; Ackerson & Preston, 2009; Blue Moon Research & Planning, 2008) is that breast cancer is symptomatic and that women do not need to participate in screening in the absence of breast symptoms. For example, Ackerson & Peterson (2009) noted evidence that indicated women who do not understand the risk/causes of cancer believe they are not at risk of developing this disease. They assume they are healthy and do not perceive 'routine exams' as part of the status quo or understand screening's role in detecting breast cancer at an early stage when treatment options are the greatest. Comment from other researchers is discussed in the following *subsections*.

### Silence may limit Aboriginal and Torres Strait Islander people's knowledge of and understanding about breast cancer

We identified one narrative literature review (Shahid & Thompson, 2009) and three observational studies (Pilkington et al., 2017; Treolar et al., 2013; Shahid et al., 2009), which reported findings on knowledge and understanding of cancer among Aboriginal and Torres Strait Islander peoples. The observational studies included participants from New South Wales or Western Australia. Study participants' lack of knowledge about breast cancer and the role of fear and silence in perpetuating lack of knowledge was a finding common to both studies and the literature review.

Shahid & Thompson (2009) undertook a literature review of epidemiological and qualitative studies that similarities and differences in Indigenous people's understanding and beliefs around cancer in Australia, Canada, New Zealand and the United States. The literature review did not focus exclusively on breast cancer, but it included two older papers (McGrath et al., 2006; Prior, 2005) on Aboriginal and Torres Strait Islander people's views on cancer.

Overall, eight beliefs about cancer emerged from five qualitative research studies. Shahid & Thompson included quotes from the published literature to demonstrate those beliefs. For seven of the eight beliefs, there were quotes from the two Australian papers. We have included below the beliefs and the quotes that were specific to Australian women in *Table 1* (below).

Shahid & Thompson commented that overall the literature reveals a generally pessimistic attitude towards cancer in Indigenous communities (including those in Australia), with most people viewing cancer (in general) as a frightening disease associated with death. Shahid & Thompson noted that McGrath et al. found many Indigenous people retained their traditional belief system and may have little understanding of the biomedical underpinning of cancer. In a further study (Shahid et al., 2009), the authors interviewed 37 Aboriginal people with direct or indirect experience of cancer. It was not clear from the study description how many participants had a direct experience with breast cancer itself. Shahid et al. noted that spiritual causes of illness are underpinned by traditional belief systems.

Shahid & Thompson (2009) also explored beliefs that Aboriginal and Torres Strait Islander people do not get cancer, which may stem from the finding that there is no word for cancer in Indigenous languages, one of those studies being Australian (Prior, 2005). They commented that Prior identified the reluctance by Aboriginal and Torres Strait Islander people who had survived or were dealing with cancer to talk about cancer in their community, and the attribution of payback sometimes leads to acceptance of the disease. Additionally, there was a belief that cancer is contagious, which can lead to "social and emotional isolation" for the person who has been diagnosed as it is viewed as a disease that is tainted by the alienation it causes (Shahid et al., 2009).

 Table 1: Beliefs about cancer of the Indigenous peoples of Australia and supporting quotes from three Australian studies (two included in the overview by Shahid & Thompson, 2009) and Shahid et al. (2009)

Belief	Findings
Cancer means death	When I hear the word, I feel fear. It is the big C you know, frightening, it means you're going to die (quote from Prior, 2005)
	<i>I'd kill myself if I got cancer, I couldn't have all that pain and suffering</i> (quote from Prior, 2005)
	Shahid et al. (2009) also reported this, noting that deep fear is a key reason why people may not access care even when symptomatic. While fear is universal, improvements in treatment options may not be fully appreciated or understood (eg, pessimism is a key factor).
Cancer is a "white man's disease"	It wasn't here before the 'Whiteman'. In the old days we were healthy, never had any problems. We eat bush food, possum, kangaroo meats, bush berries and all that. We did not know about cancer, did not know what it was. No one had it (quote from Prior, 2005)
Punishment/cursed/payback	Aboriginal and Torres Strait Islander cancer these days, Aboriginal and Torres Strait Islander people they think different way. Frightened someone put that cancer in their body, someone trying to curse them. (quote from McGrath et al., 2006)
	Maybe that payback thing maybe they – some people might think its payback and that's why they accept, you know the death (quote from McGrath et al., 2006)
Bodies are sacred	<i>Our body is a creation of God that should not be interfered with no matter what happens</i> (quote from Prior, 2005)
	<i>We have to respect God's work. Our bodies are sacred</i> (quote from Prior, 2005)
Cancer is contagious	<i>A lot are frightened they may catch it too, yeah</i> (quote from McGrath et al., 2006) This myth was also identified by some participants in Shahid et al.'s 2009 study.
Destiny/fatalism	What can be done about it (cancer)? It can't be cured, can it? No one can stop it; I don't really like talking about it because it makes me feel

Belief	Findings
	<i>sad; Talking could make it happen, tempt fate</i> (all quotes from Prior, 2005)
	I don't think that it's something you can prevent, it's just people are chosen you can go and have tests every six months, and one day you could just have it and it's been there the whole time (quote from Shahid et al., 2009)
Cancer is not a priority	I have been here 9 months, worked here 5 years (with Indigenous people) and the cancer numbers are small (from McGrath et al. 2006)

Pilkington et al. (2017) undertook a qualitative study involving interviews, focus groups and yarning sessions with 65 Aboriginal and Torres Strait Islander consumers and health professionals from Western Australia to examine perspectives on cancer screening among Aboriginal and Torres Strait Islander peoples in Western Australia. Most (59/65 study participants) were women.

Many participants described a general lack of knowledge and awareness around breast cancer (and screening), with one participant providing the following quote which she believed reflected a sentiment held by many Aboriginal and Torres Strait Islander peoples:

# There is nothing there, there is no lump there so there is no reason I should go.

This was Pilkington et al.'s only finding specifically about Aboriginal and Torres Strait Islander people's knowledge of breast cancer (that it needs to be symptomatic to be detectable), and it was not elaborated on further; however, Shahid et al. (2009) also reported that interview participants had a low understanding about cancer, attribution of cause and cancer symptoms in general and some had a low awareness of the importance of self-awareness and self-examination this indicates that even symptomatic presentations may not result in a choice to seek symptom assessment.

Pilkington et al. also described broader beliefs and perceptions among Aboriginal and Torres Strait Islander peoples in Western Australia and reported fear as a finding (both fear of screening results and fatalistic beliefs around cancer) (similar to the findings presented by Shahid & Thompson and Shahid et al., 2009). The belief of cancer being a death sentence (and that women would rather not know at all than find out they have cancer and have to undergo unpleasant treatment when they see death as inevitable) was demonstrated by a quote from one participant:

#### You think sometimes it might be because they are scared of finding that they have got breast cancer. I know some women still think that if you get breast cancer it is a death sentence.

Treolar et al. (2013) examined individual, social and cultural aspects of health literacy relevant to cancer among Aboriginal and Torres Strait Islander peoples. This study had 56 participants, most of whom were women: 22 had been diagnosed with cancer, 18 were carers of Aboriginal and Torres Strait Islander people with cancer, and 16 were healthcare workers. Most study participants lived in the eastern metropolitan and non-metropolitan areas of New South Wales. Half of the healthcare workers were Aboriginal and Torres Strait Islander peoples, and half were not. Participants' self-selected results were reported from semi-structured, in-depth interviews. Regarding recognising susceptibility to cancer, both patients and carers described that they had limited knowledge of cancer, experience or expectation of cancer prior to the diagnosis that affected them. Treolar et al. highlighted the following views of cancer from study participants, which again reflect other studies of Aboriginal and Torres Strait Islander people's beliefs about and attitudes towards cancer:

- Community understandings of cancer are imbued with myths and misunderstandings.
- A cancer diagnosis equates to a death sentence.
- Aboriginal and Torres Strait Islanders did not expect to experience cancer in their life, a view which worked to silence discussion and acted as barriers to screening, and
- The absence of Aboriginal and Torres Strait Islanders in campaigns reinforces silence.

Some study participants raised that cancer was 'new' for Aboriginal and Torres Strait Islander communities: Treolar et al. commented that this perception may be influenced by prior instances of death from cancer that were not noted as such or described as something else. The following quotes from study participants demonstrate some of these understandings:

A big silent word ... you mention cancer and God, every-body just caves in.

.... There's also some degree of lack of education among our people so .... you have some families who might abandon the person who has cancer because they are too frightened by it and they think cancer is a death sentence, so as soon as the diagnosis comes, they shut down with fear.

Treloar et al. noted that among Aboriginal and Torres Strait Islander people in their study, some beliefs, and particularly beliefs equating cancer to death, differed from mainstream Western biomedical views of the body and cancer and that this serves to silence discussion of cancer. This paper also explored the influence of these beliefs on choice to participate cancer screening (see *section 3.3*). Treolar et al. recommended caution in generalising the results of the study to other communities which may have different cultural understandings that may impact health literacy.

Studies suggest that there are differences in CALD women's knowledge of breast cancer, with some believing that breast cancer may affect them and others believing in fatalism, that cancer is a 'Western woman's' disease and that talking about cancer incites back luck

Two papers presented information on CALD women's understanding of breast cancer.

Cullerton et al. (2016) conducted an evaluation of a pilot cancer screening module (undertaken in 2012) aimed at determining the impact of education sessions on knowledge, attitudes and intentions to participate in screening for CALD communities living in Brisbane, Queensland. As part of this study, Cullerton et al. presented baseline data on women's knowledge of breast cancer. A total of 61 women participated in a breast screening education session: 33 women (54.1 percent) were aged 35-64 years, 14 women (22.9 percent) were younger than 35 years and eight women (13.1 percent) were aged 65 years and over. The cultural groups included in the breast screening education sessions included Arabic-speaking, Bosnian, Indian, Samoan, Spanish-speaking, Sudanese and Vietnamese women. Cullerton et al. provided study participants with two statements to elicit their knowledge of breast cancer and only <u>one</u> risk factor (age):

- 1. A person can have breast cancer even if they feel well, and
- 2. The risk of getting breast cancer increases with age (which is discussed in *section 4.1.2*).

Cullerton et al. also reported baseline data on three attitudinal statements about breast cancer:

1. It is possible that I will get breast cancer in the future

- 2. I am more likely to develop breast cancer than other people, and
- 3. Thinking about breast cancer scares me.

Women's knowledge was assessed on a seven-point Likert scale: one (completely disagree) to seven (completely agree). Women generally agreed with both knowledge questions. Out of a possible median score of seven (± standard deviation), the median pre-education session, or baseline data finding for the statement '*A person can have breast cancer even if they feel well*', was 6.0 (interquartile range 4.0-7.0). No further comments about this finding were provided.

For the 61 women who participated in the breast cancer education session, although there was some variation, they generally agreed that it is possible they would get breast cancer in the future and that thinking about cancer scared them, while they were generally more neutral about their likelihood of developing breast cancer than other people. The media and interquartile ratings for the three attitude-based questions is presented below in *Table 2* (below).

Attitudes	Median	Interquartile range
It is possible that I will get breast cancer in the future*	6.0	4.0-7.0
I am more likely to develop breast cancer than other people*	4.0	3.0-6.0
Thinking about breast cancer scares me*	6.0	5.0-7.0

 Table 2. Median pre-education session ratings on cancer attitudes among CALD groups in Brisbane, Australia from

 Cullerton et al. (2016)

\*Median score out of a possible 7 ± standard deviation.

Another paper that provided baseline findings on women's attitudes and perceptions of breast cancer focused on Chinese-Australian women (Kwok et al., 2011). Kwok et al. reported on the evaluation phase of a culturally sensitive breast health education program, Living with Healthy Breasts, Be a Breast Health Advocate'. They authors conducted interviews with 37 Chinese-Australian women in Sydney, exploring women's responses to a number of beliefs about breast cancer.

Before we discuss the findings of this study, two other articles by Kwok et al. (2012, 2011) referred to articles they had published in 2006 (outside of the inclusion dates of this literature review) on the role of breast health practices and the influence of traditional Chinese beliefs on cancer screening choices among Chinese-Australian women. While we have not gone back to these papers, we have included the findings from the papers as reported in Kwok et al.'s 2011 paper as they provide additional insight into the attitudes and beliefs of Chinese-Australian women regarding breast cancer. Of relevance to this literature review were that:

- the discussion of breast cancer is considered to be inappropriate in the Chinese culture as it is believed to bring bad luck
- the best way of "preventing" the onset of breast cancer is to avoid cancer-related thoughts
- fatalism is a cultural belief (and affects participation in breast screening, which we discuss further in *section 3.3* of this report)

- Chinese-Australian women perceived breast cancer as a 'Western women's disease', and
- there is no reason to have a mammogram if a woman is not sick: there is a tradition that women only see a physician when there is a specific problem, not to prevent or look for one.

These findings reflect those for other cultural groups discussed in this review. In Kwok et al.'s 2011 study, the baseline (pre-education program) beliefs of Chinese-Australian women have a high awareness of breast cancer, including that:

- most (92 percent) agreed breast cancer was the leading cause of cancer (eight percent did not know)
- most (89 percent) disagreed with the belief that cancer is like a "death sentence" (if you get cancer you will die) but 11 percent did not know if it was a "death sentence"
- all agreed that breast cancer was curable if detected early
- most (84 percent) disagreed that feeling well meant there was no reason to worry about developing breast cancer, while 11 percent did not know, and three percent agreed
- about half (54 percent) disagreed that a lack of physical symptoms means little chance of having breast cancer, while 19 percent agreed and 27 percent did not know, and
- most (78 percent) disagreed that thinking about breast cancer will cause it to happen, 11 percent agreed, and 11 percent did not know (which differs slightly from some of Kwok et al.'s earlier findings).

Regarding Chinese-Australian women's readiness to discuss breast health (and consistent with previous findings that the discussion of breast cancer is considered inappropriate in Chinese culture since it is believed to be bad luck), Kwok et al. reported that the majority of women said they had seldom discussed breast cancer previously with peers or family members, and all agreed the issue remained sensitive. The authors acknowledged the study's limitations around generalisability (conducted in one city, with a small group of women primarily from Hong Kong who had a high level of English proficiency).

# 4.1.3. Australian women's knowledge of specific breast cancer risk factors varies but our understanding of awareness is limited by a lack of data

We did not find any systematic reviews or literature reviews that addressed Australian women's knowledge or understanding of breast cancer risk factors (either generally or in relation to specific risk factors). We identified two observational studies that provided comments on Australian women's knowledge of understanding or baseline information from studies where the impact of an educational intervention was studied. As such, the available literature is limited and relates to specific sub-population groups of Australian women. More general information about Australian women's understanding of breast cancer risks factors was presented in Blue Moon Research & Planning's 2008 qualitative research. While the authors are clear that the sample size for this work means that it is not possible to generalise to the broader population, the Blue Moon research indicates that Australian women (represented by regular, lapsed and never screeners) probably have a fairly poor understanding of the risk factors for breast cancer. These findings are discussed in the following sections.

#### Age

Cullerton et al.'s evaluation of a pilot cancer screening module asked women whether 'the risk of getting breast cancer increases with age' (methodology described in section 4.1.1). The median was 6.0 on a sevenpoint Likert scale (interquartile range 5.0-7.0). No mean was given. This indicates a fairly good understanding of age as a risk factor for breast cancer among the study population.

Blue Moon Research & Planning (2008) (methodology described in *section 4.1.1*) noted that research participants' understanding varied, with some thinking that breast cancer is more common at younger age ranges

than it is. The Blue Moon authors noted that this was potentially due to media coverage of breast cancer in younger women or celebrities aged under 50 years. Women's more limited understanding of increasing age as a risk factor for breast cancer was also discussed in other grey literature. For example, Open Mind (qualitative research of 545 under-screened women in Victoria) reported that only 63 percent of participants correctly noted that increasing age is the biggest risk factor for breast cancer, with 57 percent knowing that over 75 percent of breast cancers occur in women aged over 50 years. The evaluation of the BreastScreen Australia program also reported limited understanding of increasing age as a risk factor for breast cancer, noting that the poor understanding of this risk factor led to misunderstandings by Australian women about the reason for the program's approach to actively inviting women aged 50 to 74 years to participate, but also being open to women aged 40 to 49 years and 75 years or over.

#### **Family history**

Understanding the risk posed by a family history of breast cancer was explored in Ackerson & Preston's 2009 literature review on why some women with access to care do not seek cancer screening (see *section 4.2* for a full discussion of this review). The authors noted women underestimated risk for cancer when they do not have a family history of the disease. The authors citing evidence that those without a family history did not perceive themselves as at risk and, therefore did not think they needed to obtain a mammogram or participate in routine screening. This finding was also present in the international literature (eg, Katapodi et al., 2009) as well as in other grey literature. For example, Blue Moon Research & Planning (2008) (methodology described under *section 4.1.1.*) participation qualitative research also noted that study participants had a low awareness of the dimensions of family history as a risk factor: women A woman with one or more firstdegree relatives (parent, sibling, child) with breast cancer has two times the risk of developing breast cancer compared to a woman with no family history. Most women who develop breast cancer do not have a family history.

(including never, lapsed and regular screeners) tended to believe that because they did not have a family history, there were at a low-risk of developing breast cancer. This finding (that women thought they will not develop breast cancer because there is no family history or lack of knowledge that nine out of ten breast cancers occur in women with no family history) was replicated across a number of studies commissioned by BreastScreen Australia programs (including Essence, 2011; Open Mind, 2012).

Some researchers also reported that because women are questioned about family history on breast screening consent forms/personal questionnaires (and most BreastScreen Australia programs specially ask about personal or family history of ductal carcinoma in situ (DCIS), breast and ovarian cancer), they may overestimate the importance of this risk. Quantification of these responses was not provided. The over-importance placed on family history (or lack of it)

Increasing age is the strongest risk factor for breast cancer. More than 75% of breast cancers are diagnosed in women aged over 50 years. by women was the reason for BreastScreen NSW's 2018 campaign, *Not in my Family*, which increased recognition of the statistic that nine out of ten women with breast cancer do not have a family history among women aged 50-69 years. Information about personal questionnaires is included in *section 5.5*.

Other dimensions of women's understanding of family history were explored in Thomson et al.'s (2014) case-control study using a risk perception questionnaire to explore women's understanding of breast cancer risk/protective factors. In this study, 1109 Western Australian women who had a breast cancer diagnosis and 1633 Western Australian women without the disease were asked about their perceptions of risk with a view to understanding whether there were differences between women based on a cancer diagnosis. The cohorts had very different understandings of the role of family history:

- women without breast cancer thought that family history or inherited characteristics were the most significant cause of breast cancer (77.6 percent of women), but
- women with a breast cancer tended to attribute the cause of their cancer to lifestyle factors and hormonal history: only 28.7 percent noted that family or genetic history was a risk; as noted by the authors, this may be because women with cancer have a good understanding of the specific nature of their own cancer (rather than revealing specific differences in baseline understanding).

Fear among women with a high familial risk of breast cancer can lead to inaccurate perceptions of the risk of developing breast cancer. In a recently published qualitative study of 46 Australian or New Zealand women aged under 35 years and who had a strong family history of breast cancer. Interestingly, the authors included both family history (defined as a first-degree diagnosed with breast cancer) and genetics (BRCA1 or BRCA2 mutation) in the definition of strong familial history. In total, 36 study participants were BRCA carriers and ten had an unknown BRCA status), Glassey et al. (2018) identified fear as an influencer of women's risk perception. While this paper was mostly about women who were considering or who had undergone bilateral prophylactic mastectomy, it reported that study participants held heightened and sometimes inaccurate perceptions of risk. Underlying anxiety and fear, individual participant differences, and information about breast health and screening from health professionals or organisations that induced fear were all factors that influenced how these young women perceived their risk of developing breast cancer. Some women who had no known genetic predisposition to breast cancer still believed it was inevitable they would develop breast cancer and were extremely anxious. The authors noted that communicating about risk was an important next step for supporting women to reduce anxiety about the potential to develop breast cancer.

In an older study, but also on women at higher familial risk of breast cancer, Keogh et al. (2011) undertook a qualitative study involving 24 women aged 35 to 70 years to determine how a population-based sample of women who have not had breast cancer and who are at increased but unexplained familial risk of breast cancer perceive their risk of breast cancer, and how it is related to screening choice. From the interview data, women were classified into one of five groups, which the authors referred to as 'risk management styles': these are discussed further in *section 3.3 (Relationship between women's understanding and participation in screening)*. These styles considered not only what women said about their risk, but how they felt about their risk and what they said they did about their risk. Regarding risk perception, Keogh et al. noted the women in this study had not discussed risk with a genetic counsellor and therefore relied heavily on their own interpretation of their breast cancer risk. They found no direct positive association between the number of family members diagnosed with breast cancer and perceived
risk and that women's statements about their perceived risk (for example, *'middle road'* or *'one in three'*) provided only a portion of the information needed to understand their risk perception.

Fear was a finding in two studies that investigated risk perception among women at increased familial risk of breast cancer, one that looked at risk perception in young women aged under 35 years and one where women were recruited from a population-based sample. The studies tend to focus on specific population groups including Aboriginal and Torres Strait Islander peoples, Chinese-Australian women and CALD women. Pilkington et al. (2017) reported that This fatalistic attitude can prevail in Aboriginal and Torres Strait Islander peoples with a family history of cancer (and who are often reluctant to have a screening mammogram) because "they think they're going to get it [cancer] anyway".

No comment was provided on other risk factors relating to genetics.

#### **Genetic risk**

We did not identify any published, peer-reviewed literature that looked at Australian women's understanding of the relationship between breast cancer and genetic risk (such as a BRCA1 or BRCA2 mutation, low penetrance single nucleotide polymorphisms, or other genes with a known risk link to breast cancer). Glassey et al.'s 2018 study did include women with BRCA1 and BRCA2 mutations. The results of this study are discussed in the previous subsection on family history. Similarly, Thomson et al.'s case-control study based on a risk perception questionnaire asked for information about women's understanding of family history but also included genetic risk (also discussed in the previous subsection). The authors noted that women's perceptions about cancer as an inherited disease are important as it might provide a false sense of safety from this disease, which screening programs need to consider when developing marketing material. Some grey literature also noted women's more limited understanding that most breast cancers are not caused by genetic factors (for example, Open Mind, 2012, reported that only 47 percent correctly identified that most breast cancers are not caused by genetic factors).

#### **Breast density**

For this literature review, we did not identify any literature on Australian women's knowledge on breast density as a risk factor for breast cancer. We are mindful that research has been undertaken with women in Western Australia regarding their knowledge of breast density as a risk factor for breast cancer and its masking effect on mammograms. This research (led by Dr Stone) has yet to be published but will provide useful information once it is available. This research is likely to cover women's knowledge of breast density, their actions after being advised that they have dense breasts and how this impacts their emotions and intention to screen and the perception of risk. Increased density increases the risk of developing breast cancer compared to other women of the same age with less dense tissue, but the size of the association depends on which groups of women are compared.

We have previously described a literature review on breast density knowledge and breast density awareness by Santiago-Rivas et al. (2016) in *Allen + Clarke's* 2018 review of the evidence on breast density and

screening. All studies in Santiago-Rivas et al.'s work was published in the United States between 2013 and 2015. A summary of the findings from Santiago-Rivas et al. (2016) indicates that there is some awareness of breast density as a risk factor for breast cancer (although this may reflect the notification practices in the 31 US states). Findings included that:

• Results from a national survey of 1,506 American women administered to women aged 40 to 74 years using an online service reported that 57.5 percent of participants

responded "yes" to the question, "have you ever heard of something called breast density?"

• Women who participated in a small study (*N* = 77) conducted at a breast clinic responded to the item "Do you know what breast density is?" by using a scale from 1 (I have never heard about it) to 5 (I know exactly what it is). Results showed that the average response to this item was 3.64 (*SD* = 1.29).

Santiago-Rivas et al. (2016) also reported that, generally, a relatively low proportion of women knew their own density status, and there was a general lack of knowledge regarding the association between increased breast density and breast cancer risk. The review found that increased breast density knowledge seemed to be associated with sociodemographic and screening history factors, such as race, ethnicity, household income, and history of diagnostic evaluation after a mammogram. For example, two of the three studies that assessed breast density knowledge by race or ethnicity found that, on average, white women had significantly more knowledge about breast density than non-white women. The authors also noted that their review findings suggest a need to inform women about breast density in general. Application of this level of knowledge to Australian women is uncertain as notification and reporting of breast density to individual women is not a routine part of all BreastScreen programs (whereas reporting is mandatory in most US states). It is logical to assume that fewer women in Australia might be aware of breast density and cancer risk given this is not reported through all BreastScreen programs.

#### Modifiable risk and protective factors

Modifiable risk factors include diet, exercise, smoking status, alcohol consumption and the use of hormone replacement therapy during menopause. The Blue Moon Research & Planning (2008) participation qualitative study indicated women had some familiarity with other risk factors including hormone replacement therapy (and menopausal status, especially if they had been through menopause early). Likewise, participants (both women assigned to the case and control cohorts) in Thomson et al.'s 2014 case control study (methodology described in the section on *Family History*) also identified use of HRT as a risk factor,

Use of combined HRT increases risk of cancer and the risk increases the longer a woman uses HRT but it decreases when treatment stops

noting that women in both groups (with/without a breast cancer diagnosis) understood that there are modifiable risk factors (38.6 percent and 47.1 percent respectively), which include HRT, alcohol consumption and diet. HRT was identified by 13.7 percent of women with cancer (cases) but fewer control women appear to identify longer-term HRT use as a risk factor (possibly due the questionnaire or because women with cancer had been given further information about the use of HRT and cancer by their health care providers). No further detail about women's understanding of HRT use and breast cancer was supplied; however, we note that most BreastScreen Australia consent forms/personal questionnaires ask women about current HRT use (see *section 5.5*).

McBride et al. (2019) completed a small qualitative interview-based study investigating obese women's attitudes toward breast cancer and screening. The authors interviewed 19 women with a BMI of >30kg/m<sup>2</sup>, noting that only one participant identified her weight as a risk factor for breast cancer.

Thomson et al. (2014) also noted that women in the control group were more likely to discuss diet, physical activity and alcohol consumption as modifiable risk factors than women with a cancer diagnosis. Alongside the modifiable risk factors, women in Thomson et al.'s 2014 study also identified protective factors like a healthy and balanced diet, regular moderate to vigorous exercise and low alcohol consumption and maintaining a healthy weight as being important. Women participating in Blue Moon Research & Planning's 2008 research also briefly explored women's understanding of protective factors, noting that a small number

Protective factors include being physically active, maintaining a balanced diet and breastfeeding for more than 12m.

of women reported breastfeeding and younger age of having a baby and the importance of diet as being protective against breast cancer, but this was not explored in detail. BCNA (2018) noted that women do not have a good understanding about the alcohol consumption, with uncertainty about its role as a risk factor for breast cancer.

#### Misunderstandings about breast cancer risk factors

Blue Moon Research & Planning (2008) also identified some myths and misconceptions about breast cancer risk and protective factors. These included stress, pollution, radiation (indicating generally poor understanding about the link between ionising/non-ionising radiation and cancer and the radiation dose associated with mammography), compression in a mammography unit, and being hit in the breast.

### 4.2. Australian women's knowledge and awareness of and attitudes towards population-based breast screening

*Section 4.2* of this report describes the findings presented in published, peer-reviewed literature and grey literature for research question 2:

What are women's attitudes towards and perceptions of the risk of breast cancer (individual risk and general population risk) and the benefits, risks and limitations associated with participation in an organized breast screening program?

Information presented in *section 4.2* specifically focuses on women's understanding of population-based breast screening. Information about breast cancer risk and protective factors is described in *section 4.1*. Information about women's understanding of the benefits and limitations of breast screening are included in *section 4.3*. The papers discussed in this section of the literature review are listed below and overleaf.

#### Systematic review

One systematic review: Seaman et al., 2018

#### **Observational studies**

Six observational studies: Ogunsiji et al., 2017; Cullerton et al., 2016; Hersch et al., 2015; Kwok et al., 2015; Hersch et al., 2013; Kwok et al., 2011.

#### **Grey literature**

Two papers: Open Mind, 2012; Blue Moon Research & Planning, 2008

#### **Key findings**

### From limited studies, Australian women appear to know about mammography but knowledge about the benefits and harms is variable

We know more about women's knowledge about, awareness of and attitude towards populationbased breast screening. Most studies indicate that Australian women are aware of mammograms or are breast aware but there is less than awareness of the recommended age to start screening (although they understand the recommended frequency of BreastScreen Australia screening). There appears to be a wide range in women's accurate understanding of the purpose of screening using mammography: less than one-third of Australian women understand a purpose of mammography is cancer detection. Other areas of areas of variable understanding include that breast screening is for asymptomatic women and what false positives are and their impact on subsequent investigation for final benign results.

#### Overdiagnosis is poorly understood

Recent evidence indicates women's awareness of overdiagnosis is low and that women do not understand the concept of overdiagnosis well (this matches broader population limitations in understanding of overdiagnosis). In addition, women also do not appear to understand mortality reduction well and tend to overestimate the benefit of screening and underestimate the harms; but we do not really know much at all about Australian women's understanding of mortality reduction.

#### But women believe in breast screening as useful and life-saving

Women generally perceive mammography programs as useful, life-saving, the best way to detect cancer and that these programs are more beneficial than harmful. Older and very limited evidence suggests few women are concerned about radiation associated with mammography.

*Section 4.2* draws heavily on Seaman et al.'s 2018 review (described below) and the Australian papers covered in that review. The evidence suggests that women understand that screening is for well women, but nuances in the research and findings might explain findings about cancer understanding that suggest women think they should attend for screening if they are symptomatic.

#### Summary of Seaman et al.'s 2018 systematic review

Seaman et al.'s 2018 systematic review provided insights on women's knowledge of breast screening across ten areas, including risks and benefits of mammography. The authors undertook a systematic review of literature published between 1992 and 2017 from countries participating in the International Cancer Screening Network (ICSN) Breast Cancer Division to understand women's knowledge of screening by mammography. The search strategy, data sources, inclusion/exclusion criteria, data extraction process, risk of bias assessment, and analysis strategy were specified *a priori* and followed the PRISMA guidelines. Inclusion criteria for the systematic review were:

- studies reporting original data on women's knowledge/understanding/awareness of screening mammograms and published in or translated into English
- intervention studies where pre/post knowledge was collected and responses to policy changes or knowledge of recommended guidelines
- studies that reported data from countries that are members of the ICSN Breast Cancer Division and had/have a national population-based mammography screening program at the time of the research, and

• studies with participants who were women aged 40 years or older (i.e., the age at which screening recommendations begin but where this was ambiguous, the percentage of women over the age of 40 within the sample had to be 50 percent or more or the mean age be 50 years or more).

A total of 35 studies met the inclusion criteria. Of these, 26 were quantitative (21 employed a cross-sectional design, four used a randomized controlled trial design and one used a quasi-experimental design). Nine were qualitative studies, which predominantly used focus groups (n=six) and three used one-on-one interviews. Eleven studies were conducted in Australia and were published between 1995 to 2015, with five studies published in the last ten years, and several published before 2000. The Australian studies were: Hersch et al. (2015); Kwok & Lim (2015); Hersch et al. (2013); Mathieu et al. (2010); Villanueva et al. (2008); Mathieu et al. (2007); Achat et al. (2005); Barratt et al. (1999); Cockburn et al. (1999); Barratt et al. (1997); and Cockburn et al. (1995).

# 4.2.1. Most Australian women are aware of mammography and/or have heard of and/or practice breast awareness but there is variation in understanding of breast exams between different groups of women

Seaman et al. (2018) looked at nine studies of women's awareness of mammography in their systematic review, three of which were Australian studies (Kwok & Lim, 2015; Achat et al., 2005; Barratt et al., 1997). Overall, women's awareness of mammography ranged from 47.2 percent to 99.9 percent, with the Australian studies being more in the mid-range to higher end. Specific data from the Australian studies was:

- 69.4 percent reported by Kwok & Lim (2015)
- 99.8 percent reported by Achat et al. (2005), and
- 63.2 percent reported by Barrett et al. (1997), which also found higher levels of awareness associated with older age (women aged 50-69 years) and post-secondary school qualifications.

Women's awareness of the BreastScreen Australia program was also reported as high in the Blue Moon Research & Planning research (2008), although the level of awareness of the program was not quantified. Some groups (women with complex lives, Arabic or Vietnamese-speaking women, younger women and those not engaged in primary care) had lower levels of understanding. Other groups of women (including Australian-Chinese, Australian-Greek and Aboriginal and Torres Strait Islander peoples had a higher awareness of the program). There was also a range of information provided by BreastScreen Australia programs which also indicates that women have a good understanding of mammography. For example, research on 545 under-screened women (Open Mind, 2012) found that women understand that:

- early detection offers the best chance of successful treatment and recovery (97 percent)
- mammography is the best way to detect cancer early, when it is very small and that this test should be completed every two years by women aged 50 to 69 years (92 percent, 84 percent and 88 percent respectively), and
- the dimensions of the BreastScreen Australia program are free screening by mammography every two years (77 percent) and that fewer than one percent of women screened are found to have breast cancer (28 percent).

We found four observational studies that reported on awareness of breast health and mammograms in population groups of Australian women, including Chinese-Australian, Indian-Australian and African migrant women. Awareness of breast awareness and mammograms was generally high (more than three-quarters of study participants across all studies had heard of mammography).

Ogunsiji et al. (2017) completed a descriptive, cross-sectional study investigating breast screening status and the factors associated with the breast screening choices of 264 African migrant women aged 18 to 69 years and living in Australia. Ogunsiji et al. used an African version of the Breast Cancer Screening Beliefs Questionnaire. The authors reported that most of the women in their study had heard of breast awareness (76.1 percent) and of a mammogram (85.2 percent) but less than half of women (42.5 percent) had ever heard of clinical breast examination. Even higher rates (92.0 percent) for women in the eligible age range for screening (between 50 and 74 years). While about three-quarters of the women had heard about breast awareness and mammography, a very low proportion (11.4 percent) examined their breasts monthly. The authors noted their findings were consistent with previous research including Kwok et al. (2015). The possible explanation for the low monthly attention of African women to their breast health was linked to the high knowledge deficit about breast awareness that is common among African women along with their negative attitudes towards discussing and touching breasts.

Kwok et al. (2015) used a similar study methodology as Ogunsiji et al. (2017) to investigate the breast cancer knowledge, attitudes and screening practices of 242 Indian-Australian women aged 20 or more years (median age of study participants was 41.1 years). In this study, the authors used English language versions of the Breast Cancer Screening Beliefs Questionnaire. Overall, the majority of Indian-Australian women had heard of breast awareness (75.6 percent) and clinical breast examination (72.7 percent); however, fewer women aged 40 years and older (67.7 percent) had heard of clinical breast examination. For awareness of mammography, 75.6 percent of the women across all ages had heard of mammography, while a higher proportion (80.6 percent) of women aged 50 to 69 years had heard of mammograms.

Kwok et al. (2011) reported on the evaluation phase of a culturally sensitive breast health education program, Living with Healthy Breasts, Be a Breast Health Advocate. The paper provided baseline data on 37 Chinese-Australian women's knowledge of breast health, including mammograms. Prior to the education program, 95 percent of women had heard of breast self-examination, 81 percent had heard of clinical breast examination and 87 percent had heard of a mammogram. Additionally, 95 percent of women knew to practice breast self-examination regularly and 89 percent knew women should get clinical breast examination regularly.

Among CALD women living in Brisbane, Queensland, Cullerton et al. (2016) (methodology described in *section 4.1*) determined the impact of education sessions on knowledge, attitudes and intentions to participate in screening. The authors reported that for the 61 women who participated in the breast screening sessions, at baseline (before the education sessions), most women had heard of mammography as only 22 percent of participants had not heard of or were unsure of mammography screening.

#### 4.2.2. Women's understanding of the purpose of breast screening varies

Seaman et al. (2018) reviewed six studies that examined women's perceptions of the purpose of screening mammography, one of which was an Australian study by Villanueva et al. (2008). Of the literature overall, Seaman et al. commented that there was a wide range in accurate understanding of the purpose of screening although in the studies the purpose of screening had

been defined by the study authors and differed between studies. For example, four studies considered 'cancer detection' to be the most correct answer with the percentage of women who selected this response ranging from 20 percent to 98 percent. In Villanueva et al.'s study, less than one-third of Australian women (29.1 percent) responded correctly, with correct responses associated with increasing age and prior mammogram. Hersch et al.'s 2015 study described women's baseline understanding that a purpose of screening was to reduce deaths from breast cancer was 96 percent; however, few participants understood screening as a tool for early detection in Shahid et al.'s 2009 study.

Both Pilkington et al. (2017) and Trealor et al. (2013) noted that Aboriginal and Torres Strait Islander study participants did not think that breast cancer would affect them or that it was about finding a palpable lump, and because they were well, they had no need to participate in routine, population-based screening. Trealor in particular noted that these understandings of screening acted as barriers to a choice about participating in screening.

In Blue Moon Research & Planning's study (2008), the authors reported that some CALD women did not understand the purpose of screening (and were therefore not likely to participate in screening). Specific figures were not provided. Another key finding demonstrated that women may not understand the difference between a screening mammogram and more detailed diagnostic mammogram images and that women's understanding about the overall purpose of a screening test.

# 4.2.3. Some studies suggest that women understand that screening is for well women, but nuances in research methodologies might explain findings about cancer understanding that suggest women should attend if they are symptomatic

Seaman et al. (2018) reviewed ten studies on women's perceived necessity of undergoing screening mammography, four of which were Australian studies (Hersch et al. 2015; Villanueva et al., 2008; Cockburn et al., 1999; Barrett et al., 1997). Generally, results for understanding that screening is for asymptomatic women was high. Citing Villanueva et al. (2008), Seaman et al. reported that 94.5 percent of participants considered mammography as necessary and reported:

### 94.5 percent of women believed attendance is compulsory irrespective of the presence of symptoms.

Similarly, in the 1999 study by Cockburn et al., 97 percent of women thought they were eligible for screening irrespective of symptoms and in Barratt et al.'s 1997 study, only 1.3 percent of women in the study by Barrett et al. thought screening is only for well women. Conversely, Seaman et al. also reported on Hersch et al.'s 2015 study, which found that 88 percent of study participants thought screening is for healthy women. From the limited evidence, it appears that Australian women have become more knowledgeable over time about screening being for asymptomatic women; however, as the evidence is extremely limited, one would need to be cautious about making any assumptions of this. Differences may also be potentially explained by the qualitative nature of the studies and study population sampling (which is likely to be highly reflective of a small range of participants' views at a point in time).

We have provided more detail of Hersch et al.'s 2015 study than just the findings reported in Seaman et al.'s systematic review. This is because these findings require more context, particularly that the findings were collected after a randomized controlled trial of a decision aid and after participants had previously been given an information pamphlet from a breast screening service. As such the findings may not be generalisable to Australian women. Hersch et al.'s study also provides findings to inform several other sections in this literature review, particularly knowledge of overdiagnosis/over-treatment, attitudes to breast screening and intention to participate in screening (see *section 4.4*).

Hersch et al. (2015) completed a community-based, parallel-group, randomized controlled trial of a cohort of 879 women aged 48 to 50 years in New South Wales who had not had mammography in the previous two years and who did not have a personal or strong family history of breast cancer. The median age of women in both groups was about 50 years: intervention group was 49.7 years (49.3-50.0); control group was 49.7 (49.4-50.1). At recruitment, study participants were sent a standard screening program leaflet which included benefits of and risks associated with mammography but no information on chances of outcomes or overdiagnosis. The authors collected baseline information on demographics, stage of decision-making about breast screening, basic conceptual knowledge attitudes and intention to screen via telephone interviews between one and four weeks later. Study participants were then randomly assigned to either the:

- intervention aid (i.e., evidence-based explanatory and quantitative information on overdiagnosis, breast cancer mortality reduction and false positives), or
- control decision aid that included information on breast cancer mortality reduction and false positives but no information on overdiagnosis.

The primary outcome of the study was informed choice, defined as adequate knowledge (which 419 women in each group answered) and consistency between attitudes and screening intentions (409 women in the intervention group; 408 women in the control group). Informed choice was assessed by telephone interview about three weeks after random allocation. At baseline, Hersch et al. (2015) reported that 85 percent of women in the intervention group thought that screening was for women without symptoms, compared to 82 percent of women in the control group.

Other research links Australian women's understanding that population-based breast screening is designed for asymptomatic well women with views that no symptoms are evidence that cancer is not present. This understanding of how screening works may reflect myths and misunderstandings about the purpose of screening (including the difference between a screening mammogram and diagnostic mammogram images) and cancer outcome, and beliefs associated with fatalism and that breast cancer is always symptomatic (discussed in *section 4.1*).

### **4.2.4.** There is confusion about the eligible age range for the BreastScreen Australia program, but screening interval is well-known

Seaman et al. reviewed 12 studies on women's knowledge of recommended age guidelines for participating in breast screening. Four included studies were Australian: Kwok & Lim, 2015; Villanueva et al., 2008; Achat et al., 2005; and Barrett et al., 1997.

#### Commencing and ceasing screening

Over all studies, Seaman et al. noted up to 66 percent of women were aware of the age to commence population-based breast screening and the frequency with which to attend screening but knowledge of age to cease screening was low. Data about women's knowledge of commencement age for mammography from the four Australian studies reported variable rates. Reported rates of women who knew the correct age to commence screening were:

- 41.4 percent (Kwok & Lim, 2015)
- 41.1 percent (Villanueva et al., 2008)
- 20.5 percent (Achat et al., 2005), and

• 60.3 percent (Barratt et al., 1997).

Cullerton et al. (2016) (methodology described in *section 4.1* of this report) included two questions on knowledge about breast screening. Prior to the education sessions, only 14.8 percent of CALD women could correctly identify the age at which breast screening should start, whereas a higher proportion (39.3 percent) correctly identified the correct frequency of breast screening. Kwok et al. (2011) reported 65 percent of the women in their study knew what age group should get regular mammograms.

For women's knowledge of cessation age, all three of the studies reviewed by Seaman et al. were Australian (Villanueva et al., 2008; Achat et al., 2005; Barrett et al., 1997). In the most recent study (Villanueva et al., 2008), 24.7 percent of women provided the correct answer about cessation age for mammography; however, six in ten women (61.4 percent) believed there was no cessation age. Achat et al. (2005) and Barrett et al. (1997) reported lower proportions of women who provided the correct answer, with 15.3 percent and 12.7 percent of women providing correct answers respectively. These findings might suggest there has been some improvement in women's knowledge over time; however, in both of these earlier studies, fewer women believed there is no recommended cessation age than the 2008 study (59.9 percent in 2005, and 55.5 percent in 1997).

#### **Screening interval**

Seaman et al. (2018) reported on understanding of screening interval. For women's knowledge on the recommended frequency of screening, three of the ten studies reviewed were Australian (Villanueva et al., 2008; Achat et al., 2005; Barrett et al., 1997). The Australian studies reported knowledge rates ranging from 58.7 Percent (Barratt et al., 1997) to 74 percent (Achat et al., 2005). Seaman et al. highlighted that the 2005 study by Achat et al. had found women defined as 'ever-attenders' (defined as attended at least one screening) were more likely to know the recommended frequency then 'never-attenders', but 'never-attenders' were more likely to know the recommended age to begin screening.

### 4.3. Australian women's understanding of the risks and benefits of participating in population-based breast screening

Hoffman & Del Mar (2015) undertook a systematic review of patient understanding of the benefits and harms of tests, including screening tests, reporting that most participants overestimate the benefit of participating in a test and underestimate the harms. This provides a framework for exploring women's understanding about the benefits, risks and limitations associated with participation in screening. *Section 4.3* of this report describes the findings presented in published, peer-reviewed literature and grey literature for research question 2:

> What are women's attitudes towards and perceptions of the risk of breast cancer (individual risk and general population risk) and the benefits, risks and limitations associated with participation in an organized breast screening program?

Information presented in *section 4.2* specifically focused on women's understanding of the benefits of screening such as the earlier detection of breast cancer (leading to reduced mortality and greater treatment options); and risks such as exposure to radiation, false positive results requiring recall for further investigation for a benign final outcome, false negative results, and over-treatment/diagnosis. Information about breast cancer risk and protective factors is described in *section 4.1*. The papers discussed in this section of the literature review are listed overleaf.

#### Systematic review

Two systematic reviews: Hoffman & Del Mar, 2018; Seaman et al., 2018

#### Literature review

Two reviews: Jansen & Houssami, 2018; Hersch et al., 2011

#### **Observational studies**

Seven observational studies: Stone, 2018; Cullerton et al., 2016; Petrova et al., 2016; Bientzle et al., 2015; Hersch et al., 2015; Moynihan et al., 2015; Hersch et al., 2013

#### **Grey literature**

Three papers: BCNA, 2018; Essence, 2011; Blue Moon, 2008

#### **Key findings**

Women perceive mammography-based screening programs as useful, life-saving, the best way to detect cancer and more beneficial than harmful

Women generally perceive mammography programs as useful, life-saving, the best way to detect cancer (and reduce the risk of dying from it) and that these programs are more beneficial than harmful. It is seen as a way to avoid regret (if cancer is diagnosed early) or as a reassurance that cancer is not present. It is possible that women who regularly participate in screening feel more favourably toward screening than those who are under-screened. While understanding that breast-screening is life-saving, Australian women do not clearly understand mortality reduction, with most women overestimating this. There are implications for such positive attitudes towards breast screening as it is likely to result in an overestimation of benefit.

Australian women's awareness of the possibility of harm varies: evidence also indicates that few women understand the sensitivity of mammography or the impact of overdiagnosis

While women may struggle to correctly identify the sensitivity and specificity of mammography (with both over and underestimates reported), most women included in studies did understand that mammography might not identify every cancer; however, we note that other findings focus on women's relief at receiving at 'all clear' result and women's confusion should an interval cancer be diagnosed. Similarly, women's understanding of false positive test results varied considerably in the research.

Overdiagnosis appears to be a poorly understood health concept and one that women may not necessarily associate with breast screening (especially given. Australian research indicates that women often do not consider investigation of a lesion with a final benign outcome as overdiagnosis; rather they are grateful for a comprehensive work-up and peace of mind. This lack of understanding may impact on informed decision-making, with the majority of women being surprised that overdiagnosis exists and wanting to be informed of the risk of overdiagnosis (and what this might mean to them especially in the context of over-treatment). Other women disagreed, believing that this does not matter if women's lives are saved.

Older and very limited evidence suggests few women are concerned about radiation associated with mammography.

Petrova et al. (2016) provided a framework for considering the complex factors that influence screening decision-making, many of which are relevant to Australian women. This included the communication of complex statistical information about probability of benefit and harm. The authors noted that different components may impact on decision-making:

- higher science and health literacy is likely to lead to greater informed decision-making as women understand the content
- emotional responses may result in poorer or better decision-making: if based on fear of disease, a women may be more likely to respond to perceived benefits of screening rather than considering the harms with appropriate balance; alternatively, she may seek out more information about screening and therefore make a more informed decision (which reflects some of the work completed by Ackerson & Peterson, 2009, on the role fear can play in screening adherence), and
- positive views about the benefit of screening positively influence intention to screen and may be reinforced by screening communications focused on the benefits of participation.

#### 4.3.1. Women perceive mammography-based breast screening programs as useful, lifesaving, the best way to detect cancer and more beneficial than harmful

In the ten studies on women's perceived necessity of undergoing screening mammography that Seaman et al. (2018) reviewed, four were Australian studies (Hersch et al., 2015; Villanueva et al., 2008; Cockburn et al., 1999; Barrett et al., 1997). Using data from Villanueva et al. (2008) and Cockburn et al. (1999), Seaman et al. noted that screening mammography programs were perceived as useful, life-saving, the best way to detect cancer and more beneficial then harmful.

We also found one literature review that discussed qualitative and quantitative studies of women's attitudes to breast screening and informed choice (Hersch et al., 2011), which reflected Seaman et al.'s conclusions. Hersch et al. (2011) provided no methodology section to explain their approach but cited 38 articles in the reference section. Of the 38 articles/reports, three were from Australia, including a report from the Australian Government Department of Health and Ageing published in 2008 and two articles (Mathieu et al., 2010; Mathieu et al., 2007). We have not included Hersch et al.'s comments about the two papers by Mathieu et al. as decision aids are out of scope for this literature review. We have included the one piece of information from the Australian Government Department of Health and Ageing where it was referred to in Hersch et al.'s review. As such, this discussion article provides little information about the attitudes of women in general. The literature overall indicated there are widely held positive attitudes and often uncritical support for mammography and screening generally with Hersch et al. (2011) stating:

Women view breast screening as a way of avoiding potential regret, and reassurance from normal results is highly valued. Screening participants acknowledge anxiety about false positives but awareness regarding potential over-detection of indolent breast cancer is minimal.

From quotes in the literature, Hersch et al. (2011) identified a number of themes that illustrated women's perspectives on breast screening including the value of reassurance: taking the opportunity for early detection through breast screening is perceived as a way of minimising potential regret whereas failure to be screened puts a person at risk of preventable death.

Two recent Australian observational studies also reported positive attitudes of women towards breast screening: one study involved CALD women in Brisbane (Cullerton et al., 2016) and the other involved women in a randomized trial in NSW of a decision aid (Hersch et al., 2015).

Cullerton et al. (methodology described in *section 3.1.1* of this report) sought to determine the impact of education sessions on knowledge, attitudes and intentions to participate in cancer

screening for CALD communities in Brisbane. The authors asked three attitude questions about breast screening both before and after the education sessions. Study participants' attitudes to screening were measured on a seven-point Likert scale ranging from one (completely disagree) to seven (completely agree). The median score was out of a possible 7 (± standard deviation). Results are presented in *Table 3* (overleaf).

 Table 3: Attitudes of CALD women in Brisbane to breast screening prior to the breast screening education session and reported in Cullerton et al. (2016)

Attitudes to breast screening	Median pre-education session ratings on breast cancer attitudes among CALD groups in Brisbane, Australia (median, interquartile range)
Screening would help put my mind at rest	7.0 (6.0-7.0)
Screening would reduce the risk of dying of breast cancer	7.0 (6.0-7.0)

As well as investigating CALD women's attitudes towards participating in breast screening, Cullerton et al. also looked at women's intention to participate in mammography. Generally, prior to the education sessions, relatively low proportions of women across the cultural groups intended to have a mammogram in the next 12 months (30 percent of women from Bosnia, 33 percent from India, 40 percent from Spanish-speaking countries, and 43 percent from Samoa and Pacific Islanders); 78 percent of women from Arabic-speaking countries intended to screen.

Hersch et al. (2015) (methodology described in *section 4.1*) included questions on attitudes towards having breast screening at baseline (after participants were given the standard NSW breast screening pamphlet) and after administering the decision aid (which aimed to increase informed choice, defined as adequate knowledge and consistency between attitudes and screening intentions). The attitude questions and ratings at baseline are shown in *Table 4* (below). Women were generally very supportive of breast screening and perceived it as beneficial. As discussed earlier, the baseline findings reported in this study may not reflect the attitudes of other Australian women who had not received a breast screening information pamphlet; however, we have included the findings of the study as the women in both the intervention and control received the same information (i.e., the NSW pamphlet) prior to baseline measures of their attitudes to breast screening were collected. Attitude items were rated on a scale from strongly disagree (1) to strongly agree (5). The authors reported screening attitudes at baseline were positive overall.

 Table 4: Women's attitudes towards having breast screening among women in the intervention and control group at baseline after they had received the standard NSW breast screening information pamphlet (Hersch et al., 2015)

Attitudes towards having breast screening	Intervention group (n= 419)	Control group (n=419)
For you, having breast screening is beneficial	4.5	4.5
For you, having breast screening is harmful (reverse scored)	4.2	4.3
For you, having breast screening is a good thing	4.5	4.5
For you, having breast screening is a bad thing (reverse scored)	4.4	4.5
For you, having breast screening is important	4.4	4.5

Attitudes towards having breast screening	Intervention group (n= 419)	Control group (n=419)
For you, having breast screening is worthwhile	4.5	4.5
Mean (SD) total attitudes score	26.5 (3.6)	26.7 (3.7)

Hersch et al. (2015) also collected baseline data on women's intention to screen. The baseline findings for the intervention and control groups of women are reported in *Table 5* (below). The authors noted most women (90 percent) indicated they definitely would or were likely to have breast screening in the next few years; however, about one out of 20 women in both groups indicated they were not likely or definitely would not have breast screening. While focused on the impact of a decision-aid (which was out of scope for our review), Hersch et al. concluded that women might make a different decision about screening participation following provision of further information about overdiagnosis; however, they remain very positive in their intention to screen.

Table 5: Women's intentions about having breast screening among women in the intervention and control group at baseline after they had received the standard NSW breast screening information pamphlet (Hersch et al., 2015)

Intentions about having breast screening	Intervention group (n=419)	Control group (n= 419)
Definitely will have screening	295 (70 percent)	314 (75 percent)
Likely to have breast screening	78 (19 percent)	69 (16 percent)
Unsure	26 (6 percent)	18 (4 percent)
Not likely or definitely will not	20 (5 percent)	18 (4 percent)

Research by Blue Moon Research & Planning (2008) also reported that women have a good understanding of the benefits even if they did not distinguish between a personal benefit to themselves (i.e., early detection and better treatment options) and a benefit to the broader population-level benefits. Regular screeners were less likely to associate screening with any risks or limitations. In this research women who were lapsed or never screeners were more aware of the risks (radiation, trauma to the breast from compression, etc.)

#### Implications of a strongly positive attitude to screening for informed consent

Seaman et al. reviewed 11 studies on knowledge score, two of which were Australian studies undertaken by Mathieu et al. in 2007 and 2010 on decision aids (one for women aged over 70 years and one for women aged 40 years). Seven produced a knowledge score related solely to women's knowledge of screening mammography while four studies produced scores that examined knowledge on screening mammography and breast cancer. While Seaman et al. stressed caution in interpreting the scores of the studies as they were unable to differentiate women's understanding of screening versus breast cancer, they commented that in their analysis of data on collated knowledge scores most studies reported the majority of their sample as 'insufficiently' knowledgeable. Mean knowledge scores of the 11 studies ranged from 2.79 to 10.9. Of the Australian studies, the mean knowledge score for the 2010 and 2007 studies were 4.95 and 6.27 respectively. For the 2007 study, 83 percent of participants were defined as being 'knowledgeable'. Seaman et al. concluded the findings of their systematic review indicated women tend to overestimate the benefit of screening and underestimate the harm, thereby posing implications for informed consent.

Another important dimension of this issue is explored by Bientzle et al. (2015). In their experiment with 70 German women on how women assess information about the benefits and limitations of screening (and how this impacts on intention to screen), the authors noted that women's underlying views on screening are likely to impact on how she weighs the benefits and limitations of participating in screening. Women who tend to want to participate in screening are more likely to view the benefits more favourably than the harms and women who are less keen on screening are likely to place a heavier weighting on the harms and limitations of screening. This suggests that BreastScreen programs may need to carefully consider the underlying predisposition of regular screeners and under-screened women. This is discussed further in *section 4.5*.

### **4.3.2.** While understanding the breast screening is life-saving, Australian women do not clearly understand mortality reduction (as a quantum)

Seaman et al. (2018) reviewed seven studies that reported women's perceptions of the mortality reduction generated from participating in breast screening. None of the studies were from Australia but we have including information about these broader findings because of their consistency. Seaman et al. found a minority of women indicated correct estimates of mortality reduction but 45.6 percent to 82.6 percent of women across seven countries overestimated the mortality reduction associated with regular screening with mammography. Seaman et al. commented that while the methods of assessing mortality efficacy differed substantially between reviewed studies, all studies indicated that the majority of women overestimated the mortality reduction from screening. Given about half or more of women across seven countries overestimated the mortality reduction of mammograms, it may be reasonable to speculate that a reasonable proportion of women in Australia may also underestimate the mortality efficacy of mammography; however, as no Australian evidence was available it is not possible to confirm this.

Seaman et al. (2018) also noted that the confusion with over-estimations of mortality benefit are common, and that some researchers had suggested that may be due to positively biased information accessible to women. Seaman et al. speculated that campaigns prominent in the mid-70s to mid-90s had established a trend suggesting screening is a 'check' for healthy women and that it saves lives may have contributed to women's over estimation of mortality reduction from engaging in screening. Additionally, Seaman et al. noted that as the figure for mortality benefit has been highly debated in the research literature, citing research ranging from 15 percent to 30 percent. This debate may cause confusion to women.

Hersch et al. (2015) included a knowledge question 'screening reduces breast cancer deaths' in their baseline data collection. This baseline data was however collected after the control and intervention groups had been given the standard NSW breast screening pamphlet. In their study, at baseline, 96 percent of women in both groups thought that screening reduces breast cancer deaths; however, as information on mortality benefit may have been included in the NSW brochure as a benefit, the finding from this study may not be representative of all Australian women.

4.3.3. Australian study participants' awareness of the possibility of false positives and negatives varies: evidence also indicates few women accurately understand the sensitivity of mammograms (reporting both underestimates and overestimates)

#### Understanding of sensitivity

Seaman et al. (2018) looked at three studies on women's awareness and understanding of the sensitivity of mammography, two of which were older Australian studies (Barratt et al., 1999; Cockburn et al., 1995). Over these studies, approximately a quarter of each sample selected the correct mammography sensitivity figure. Seaman et al. commented that few women accurately understood the sensitivity of mammograms with both over- and underestimates reported. Australian data is presented below:

- Barrett et al. (1999) reported that 24.8 percent of study participants correctly selected the mammography's sensitivity, but 41.7 percent underestimated sensitivity, 32.2 percent overestimated sensitivity and 6.1 percent were unsure.
- Cockburn et al. (1995) reported 26 percent of women correctly selected mammography's sensitivity, 18 percent underestimated the sensitivity, 35 percent overestimated and 11 were unsure.

Hersch et al. (2015) (methodology described in *section 4.1*) included the question 'screening will not find every breast cancer' in their baseline data on women's knowledge (after participants had been given the standard NSW breast screening information pamphlet) and also after the decision aid had been administered. At both baseline and post-intervention, the majority of women thought screening will not find every breast cancer: 90 percent in the control group and 92 percent in the intervention group. Without knowing what information was in the NSW pamphlet and in the decision aid regarding sensitivity and specificity of cancer detection, it is impossible to generalise this study to all Australian women. Hersch et al. (2011) commented that the perspectives identified above showed a number of findings including women acknowledge some anxiety about attending for screening mammograms, awaiting their results, and having the follow-up tests that false positive results entail, and some women are concerned about the possibility of false negative results; however, many women express strong confidence in the sensitivity of mammography and emphasise the sense of reassurance gained from receiving the 'all clear'.

Reported findings from the Blue Moon Research & Planning 2008 study included that some women (number unspecified) were aware that mammography is not 100 percent sensitive, thinking that the procedure is fallible but potentially not weighting the role of interval cancers correctly. No further information was supplied.

#### **False positives**

Seaman et al. (2018) reviewed literature on breast screening harm, identifying 15 studies, five of which were Australian studies (Hersch et al., 2015; Hersch et al., 2013; Barratt et al., 1999; Cockburn et al., 1995). Ten studies reported under 'Harms' focused on false results: four were on unspecified false results of which one study was Australian (Cockburn et al., 1999), two were on false negatives of which one study was Australian (Hersch et al., 2015), and four were on false positives of which one was Australian (Hersch et al., 2015). Overall, reported figures for awareness for false positive results varied. Women's awareness of false positives varied ranging from 46.3 percent to 98 percent, with Hersch et al. (2015) reporting the highest awareness at 98 percent. Overall women's awareness of false negatives ranged from ten percent to 90 percent (Hersch et al., 2015). For unspecified false results the 1999 Australian

study by Cockburn et al. found only two percent of women sampled noted the potential for such results.

Blue Moon Research and Planning (2008) interviewed women who had been diagnosed with an interval cancer, which provided some interesting insights into the surprise that women experienced following a diagnosis and the fact the cancers may have been missed (although the research did not distinguish between missed cancers and interval cancers). This level of surprise may indicate that women are not overly clear about the possibility that a cancer may be missed on a mammogram, believing that an 'all clear' result guarantees that there is no cancer. Other participants did engage in more regular self-exams, perhaps reflecting their understanding that a mammogram result with no visible cancer may not mean that no cancer is present (or that a fast-growing cancer may not happen). Essence (2011) also noted that some women (especially those who are strong managers of their health or who have more fatalistic beliefs) cited concern about false positive results as a possible reason for not participating in breast screening.

Other findings from Blue Moon (2008) related to recall to assessment included that some women were aware that recall to assessment could cause unnecessary anxiety for a final benign outcome.

### 4.3.4. Australian women's awareness of overdiagnosis is low and they do not understand the concept of overdiagnosis well

We identified limited information about what Australian women know about overdiagnosis but, as noted in Jansen & Houssami's 2018 editorial and review of qualitative literature, overdiagnosis appears to be a poorly understood concept. This issue was not confined to Australian women as studies from the United Kingdom and the United States also indicated a low level of awareness and knowledge of overdiagnosis, both before and after education interventions were delivered.

Further findings from the Australian research informing this review (Hersch et al., 2015; Hersch et al., 2013) are discussed below and in *sections 4.1* and *4.2*.

While over-treatment is a key component of overdiagnosis, all the studies reported solely on overdiagnosis. Blue Moon Research & Planning (2008) reported that no women in their research reported overdiagnosis as a risk associated with screening (often noting that women appreciated a thorough investigation of a screening abnormality, as opposed to seeing this an invasive and unnecessary).

Seaman et al. (2018) reviewed 12 studies on women's understanding of overdiagnosis, two of which were Australian studies (Hersch et al., 2015; Hersch et al., 2013). Over all included studies, awareness of overdiagnosis ranged from 29.27 percent to 72.4 percent, with four studies reporting figures below 50 percent. In Hersch et al.'s 2015 study, Seaman et al. reported that 33 percent of study participants were aware of overdiagnosis (based on multiple choice true/false options). Only 12 percent of women knew the difference between over-detection and a false positive result. Hersch et al. (2013) involved guided discussions about overdiagnosis, and women were unaware of overdiagnosis, surprised by it and had difficulty grasping the concept.

Findings from other observational studies of Australian populations confirms Seaman et al.'s result that overdiagnosis is, generally, a poorly understood concept and that this lack of understanding does not contribute to informed choice. For example, Moynihan et al. (2015) completed a study focused on understanding Australians awareness of overdiagnosis. The study population was not only limited to women or overdiagnosis in breast screening. Moynihan et al. used a five-minute CATI with a randomly selected sample of 500 Australians. Questions asked participants if they had participated in breast or prostate screening and, if so, whether they had

been informed about overdiagnosis. Only 10 percent (95%CI: 6 percent - 15 percent) of women who reported having a mammogram also reported being informed of overdiagnosis. Almost all women (90 percent) thought that they should be informed.

Control group findings from Hersch et al.'s 2015 study also provided detail about women's baseline knowledge of over-detection, as study participants were given no information about over-detection in the decision aid provided to them. For the 419 women in the control group who were given no information in the decision aid about over-detection, their knowledge on individual conceptual items relating to knowledge on over-detection is presented in *Table 6* (overleaf). While specific to this group of women, this data may provide insight into Australian women's knowledge on over-detection generally. We have also included the findings for women in the intervention group, which demonstrated the significant increase in women's knowledge on over-detection, although some of the knowledge statements reflect that a lot of women do have a sophisticated understanding of the dimensions of overdiagnosis.

Knowledge on over-detection	Control group (n=419)	Intervention group (n= 419)	<i>p</i> value
Screening increases breast cancer diagnoses	305 women (73 percent)	332 women (79 percent)	.0289
Over-detection vs false positive distinction	52 women (12 percent)	179 women (43 percent)	<.0001
Not all breast cancers cause illness and death	137 women (33 percent)	283 women (68 percent)	<.0001
Cannot predict if a cancer will cause harm	257 women (61 percent)	326 women (78 percent)	<.0001
Cancer that might not cause problems is treated	320 women (76 percent)	363 women (87 percent)	.0001
Some women get treatment they do not need	110 women (26 percent)	314 women (75 percent)	<.0001
Over-detect more often than prevent death	276 women (66 percent)	321 women (77 percent)	.005

 Table 6: Findings reported for women's 'Knowledge' on seven statements about over-detection after administration of the decision aid (Hersch et al., 2015)

Another study by Hersch et al. (2013) was a qualitative study of 50 Australian women in Sydney, aged 40 to 79 years with no personal history of breast cancer. This study aimed to generate insights into women's conceptual understanding and interpretation of information on overdiagnosis. For the concept of overdiagnosis, Hersch et al. (2013) found that:

- 1. Women's prior awareness of overdiagnosis was minimal and limited to only a few women who had heard of it in the context of prostate cancer
- 2. The idea of overdiagnosis occurring in breast screening was surprising and challenged women's beliefs about breast cancer generally being a serious and dangerous disease. One participant was quoted as stating:

In your brain, breast cancer – if it isn't treated – is fatal. So I've never heard of that before, and I think most women wouldn't have.

3. Women often had trouble grasping how it is possible to know that overdiagnosis is occurring:

How do we know things are being over-detected? How do we know that there are some cancers that move more quickly or become more malignant than others?...Overdiagnosis assumes that these women, who have been over-diagnosed, have a cancer that is not necessarily aggressive....Who determines what's an aggressive and a non-aggressive cancer?

Additionally, as reported by Seaman et al. (2018), many women were reported to have expressed surprise or disbelief at the current limitations to distinguish between cancers that require treatment and those that may not (or which may be managed with more conservative approaches). They also struggled with the knowledge that overdiagnosis cannot be identified at the level of individual patients and there is no way to know for sure that cancer in a particular woman will remain non-threatening throughout her lifetime (therefore representing an instance of overdiagnosis). This is similar to a theme identified by Hersch et al. (2011): women's strong belief in the benefits of screening makes the notion of harm through overdiagnosis appear counterintuitive although some women do decline screening due to a view that not all knowledge is desirable.

In Hersch et al.'s 2013 study of women's views on overdiagnosis in breast screening, the authors also explored women's evaluation of overdiagnosis and reported their reactions to learning about the concept. This study involved 50 Australian women (Sydney-based) aged 40 to 79 years. Study participants had no personal history of breast cancer. These reactions included concern from some women about the implications in terms of the undesirable psychological and physical consequences of experiencing a cancer diagnosis and enduring treatment unnecessarily, the following quotes from participants demonstrating these concerns:

It could cause a lot of unnecessary stress and heartache to the person.

So you have to go through all of the rigmarole of chemotherapy, radiation, all that sort of thing, and it may not have been necessary, and those in themselves are hard to go through.

However, a few women expressed a contrasting view, and were reported to have reacted quite defensively to the concept of overdiagnosis, questioned why it mattered and disagreed with the idea that it could be considered a bad outcome to find a cancer and have treatment that was ultimately not needed. The women who held these views apparently perceived over-detection as a value laden term, wherein the phenomenon was labelled as negative without real justification. Additionally, speculation about ulterior motives behind overdiagnosis research and the implication for funding of breast screening was also raised by women in several of the focus groups, exemplified by the following quote, which not only covers the cancer but also demonstrates the support for breast screening:

I think what they're trying to do here is cut out breast screening ...or cut out the funding ... I would hate to see the funding cut for mammograms. I think it is really important that we keep it up, if that's what all this is about.

Interestingly, in this study women overall expressed little interest in quantitative information about its frequency of occurrence, with only one woman asking for information.

The concern about using overdiagnosis as a means to cut services was also noted in Jansen & Houssami's 2018 editorial. Jansen & Houssami (2018) cited an American study about women's understanding of overdiagnosis, noting that 86 percent of women study participants would still participate in screening once they were aware of overdiagnosis, suggesting that 14 percent may not. Importantly, supporting informed decision-making by providing further information about overdiagnosis/overtreatment may adversely influence some women's decision in participate in regular breast screening.

### **4.3.5.** Knowledge of breast density's potential masking impact on cancer detection in mammography-based screening

For women with very dense breasts, knowledge of her density and the role density plays in masking potential breast cancers seen on a mammogram might be considered to be a limitation of screening (it can adversely affect sensitivity). This literature review identified no studies that discussed Australian women's knowledge of the potential impact of breast density on the masking of breast cancers seen on a mammogram (although BreastScreen Western Australia routinely reports density to women in its program, and used to provide density notification to breast screening participants living in the Northern Territory). Advocacy for breast density notification is an important component of BCNA's state of the nation report as well (2018) although the report does not include much information about Australian women's knowledge or preferences (beyond supporting notification due to the decrease sensitivity of mammography in women with very dense breasts).

Given the genesis of this work (in the breast density context), we also identified one editorial paper by Stone (2018), which noted that information about what women want to know about breast density is extremely limited, noting that further work about what women know and want to know is needed. We are mindful that research has been undertaken with women in Western Australia regarding their knowledge of breast density as a risk factor for breast cancer and its masking effect on mammograms. This research (led by Dr Stone) has yet to be published but will provide useful information once it is available.

### **4.3.6.** Older and very limited evidence suggests few women are concerned about radiation associated with mammography

Seaman et al. (2018) reported that five studies suggested women perceived minimal harm from radiation in screening mammography. They noted in two studies, one of which was an older Australian study (Cockburn et al., 1999) the percentage of women expressing concerns about radiation exposure was below 20 percent; in the Cockburn et al. study only nine percent of women were concerned about radiation.

Blue Moon Research & Planning (2008) reported that some research participants who were lapsed or never screeners, cited radiation as a reason for not participating (because of concerns exposure could cause breast cancer); however, the report did not provide information about the number of women holding this view, making it difficult to assess women's overall knowledge, or extrapolate this to the wider Australian population. This view was also identified in some BreastScreen Australia program research into the reasons why some women are underscreened, with a belief that radiation exposure during mammography is dangerous being cited as a one of the 'real' reasons why women do not participate in breast screening (Essence, 2011). It is important to note, however, that this research noted that most women do not cite this as a reason for not participating, but it is a more commonly held view for women who have stronger views about managing their own health or a fatalistic view towards health and disease.

# 4.4. The relationship between women's understanding of and attitudes to breast cancer and breast screening and their participation in breast screening

*Section 4.4* of this report describes the findings presented in published, peer-reviewed literature and grey literature for research question 4:

What is the relationship between women's understanding of risk of breast cancer and the benefits and risks associated with participation in an organized breast screening program and their participation in an organizing breast screening program?

This section also reports on the findings of the literature search for the supplementary question:

How do women's knowledge/beliefs/attitudes to participation in organized breast screening change in response to information about risk of breast cancer and the benefits, limitations and risks associated with participation in a screening program?

The papers discussed in this section of the literature review are listed below.

#### Systematic review

Three systematic reviews: Kolahdooz et al., 2014; Andreeva & Pokhrel, 2013; Ackerson & Preston, 2009

#### Literature review

Two literature reviews: Jansen & Houssami, 2018; Shahid & Thompson, 2009

#### **Observational studies**

14 observational studies: O'Hara et al., 2018; Hersch et al., 2017; Ogunsiji et al., 2017; Pilkington et al., 2017; Savaridas et al., 2017; Cullerton et al., 2016; Hersch et al., 2015; Kwok et al., 2015; Hersch et al., 2013; Team et al., 2013; Kwok et al., 2012; Keogh et al., 2011; Kwok et al., 2011; Shahid et al., 2009

#### **Grey literature**

Four papers: EY Sweeney, 2019; Cancer Australia, 2012; Essence, 2011; Blue Moon, 2008

#### **Key findings**

We understand why women choose to participate in population-based breast screening and why they do not. The relationship between women's understanding of and attitudes towards participation in breast screening appears to vary by different population groups in Australia. We also know that women fear different things and this fear can drive adherence to breast screening recommendations, or it can scare women away.

- From the available literature focused on Australian women, we understand that a lack of knowledge of cancer, fear and beliefs of fatalism and cancer being a death sentence contribute to lower participation of Aboriginal and Torres Strait Islander women in breast screening; however, recognition of a higher genetic predisposition to cancer and family history of cancer can motivate participation.
- While fear and fatalism were also identified as beliefs among Chinese-Australian, Indian-Australian, and African migrant women, participation in mammography is relatively high for these groups: in the literature we reviewed, there appeared to be no significant relationship between knowledge and attitudes to screening and participation in screening in any of these population groups.
- Participation in mammography is relatively high for CALD women: in the literature, knowledge barriers were not associated with screening participation. For this population group emotional barriers were a significant factor in screening participation.
- In contrast, among Russian-speaking Australian women, participation in mammography is low; they rely on health professionals to motivate them to participate in screening. For these women, previous experience of compulsory breast screening without education of risk factors for cancer has a profound impact on future screening choices. From very limited information, for women faced with a higher risk of breast cancer, fear and fatalistic beliefs can lead to avoidance of mammography, but in this group, screening choices can also vary widely.

Other key factors include consideration of how risk perception can promote or discourage screening (from either a view that cancer is inevitable or that it will not happen; women's mindset when it comes to preventive health, or the provision of trusted advice (either from a health practitioner or friends/family). Social influences are an important component and impact on a woman's awareness of breast cancer and her participation in breast screening. There is some evidence that body image and level of comfort being touched by a stranger act as barriers to participation.

From the limited literature, providing education to women on breast cancer and breast screening can increase knowledge, reduce misperceptions about cancer and increase participation in mammography, but when information on over-detection and overdiagnosis is included in information to women about breast screening, while screening attitudes remain largely positive, women's attitudes to participating in mammography can change, including choices to not participate.

### **4.4.1.** Data on screening participation reported in published, peer-reviewed literature reveals considerable variation in screening participation by CALD women

A small number of studies reported specific information about participation in screening. We are mindful that further, much more comprehensive data is available in BreastScreen Australia program data but have included this information here for complete reporting of the studies included in this literature review.

#### Aboriginal and Torres Strait Islander women

Aboriginal and Torres Strait Islander women have a much lower two-year screening participation rate compared to the general population: 36.3 percent of eligible women participated compared to 57.5 percent in the general population (Cancer Australia, 2012).

#### Australian-Chinese women

Kwok et al. (2012) undertook a cross-sectional survey involving 988 Chinese-Australian women aged over 18 years and living in Sydney. They used the Chinese Breast Cancer Screening Beliefs questionnaire to examine the relationship between demographic characteristics, acculturation factors, cultural beliefs and having a screening mammogram as recommended. Of the 785 women who completed the questionnaire, 320 (40.8 percent) were eligible for breast screening (i.e., aged 50 to 69 years). Of these 320 women, 74.4 percent had a mammogram as recommended (every two years). One-quarter (23.1 percent) had a mammogram less often than recommended. Women who had a mammogram as recommended had a significantly higher (more proactive) attitude to health check-ups (p<.01) and perceived fewer barriers to mammographic screening (p<.01) and were aged 50 to 59 years (p<.05).

#### Australian-Indian women

Among 242 Indian-Australian women, 75.6 percent of women of all ages had heard of mammography (Kwok et al., 2015). Only a relatively low proportion of all women had actually participated in mammography:

- 33.5 percent had a screening mammogram at all, and
- 23.6 percent had a screening mammogram as recommended.

The authors noted the relatively low participation in breast screening practices was not surprising as preventive care is not common in India and there is no national breast screening program there. Within the target age group for breast screening, findings were somewhat better:

- 80.6 percent of Indian-Australian women aged 50 to 69 years had heard of mammography
- 68 percent had a screening mammogram, and
- 58 percent had a mammogram as recommended.

Kwok et al. (2015) commented that the findings for women in the eligible breast screening group was promising, as the rate was higher than both the general population screening participation rate (55.3 percent) and the screening participation rate for women from non-English speaking backgrounds (37.7 percent). As recruitment for the study was centred on more health-oriented community organisations in which rates of screening were likely to be higher, coupled with the low representation of women with poor English and from geographically isolated areas, the authors suggested caution in interpreting the results.

#### Australian-African women

Of the women who had heard of mammography and who were eligible for screening, most (81 percent) had had a mammogram, and 65.9 percent had a mammogram as recommended. Ogunsiji et al. noted that as nearly two-thirds of women had had a mammogram, the participation rate for African migrant women in mammography in their study was higher than among Australian-born women (55 percent); however, the higher rate was put down to possibly being due to the recruitment setting of the study.

#### **Other CALD women**

One paper reported on knowledge about and attitudes towards breast screening among CALD women (O'Hara et al. 2018). O'Hara et al. (2018) explored the association between health literacy, barriers to breast screening and breast screening participation of 317 English-, Arabic- and Italian-speaking women aged between 50 and 74 years in Melbourne. Overall, 69 percent of women self-reported they had had a mammogram in the past two years, 24 percent were reported as being 'under-screened' and seven percent had never participated in breast screening. Participation rates in screening within the past two years was higher among English-(70 percent) and Italian- (76 percent) speaking women than among Arabic-speaking women (48 percent).

#### 4.4.2. We understand why women choose to participate in breast screening

Blue Moon Research & Planning (2008) (methodology described in *section 4.1.1.*) identified a suite of facilitators that women cited as reasons for participating in breast screening, including that:

- early detection offers the greatest range of treatments possible (including potentially less invasive options) and the best chance of survival post-diagnosis: this reflects strong concepts relating to self-care and preventive health behaviours
- an 'all clear' result provides reassurance to women that they are cancer-free (especially if they perceived themselves as 'high risk' and, for regular screeners, this was worth any issues with embarrassment or discomfort
- being advised to participate by their GP or another trusted health professional or being advised to participate by a trusted family member or trusted friend
- satisfaction with previous mammograms, the zero-cost nature of screening, and/or the services provided by BreastScreen programs, including the communications received from BreastScreen programs such as reminder letters, and
- awareness of breast cancer (which can be a motivator or a barrier to participating in screening depending on the women's overall response to fear, as discussed in *section 4.1*).

These reasons mirror grey literature provided by BreastScreen Australia services on the reasons why women participate in initial or rescreening (EY Sweeney, 2019).

Blue Moon Research & Planning also reported on Aboriginal and Torres Strait Islander women and CALD women's motivators, which broadly mirrored the reasons provided in the bullets above (especially the role of trusted health professionals if they discuss breast screening with women, particularly Aboriginal health workers).

There were also some findings in Blue Moon's study that related to lapsed screeners considering re-entry into routine screening, with these participants noting that information about the risk of

developing breast cancer, that the exam is fast and not too painful, and the fact that treatment options are likely to be greater if cancer is detected early was likely to persuade them (i.e., more information about the benefits).

For re-screening, Savaridas et al. (2017) also noted that interaction with staff, including radiologists also has an impact on intention to continue regular screening. In their large, state-wide (Western Australia) study of 160,028 index screening episodes, the authors found that radiographer performance was a significant predictor of whether a woman attends for rescreening. Reasons provided for this were adequate provision of information about the mammogram procedure, conversation during the procedure, and a sense that they could ask questions or stop the procedure (i.e., that the control lay with them). The importance of the radiographer (and her skill at imparting knowledge) was also mentioned in BreastScreen Australia grey literature.

Data from BreastScreen programs' client satisfaction surveys also note the importance of ensuring women are comfortable and made to feel at ease, that the radiographer and staff are professional, and that the procedure is satisfactorily explained are important components of whether women are happy with their breast screening experience (EY Sweeney, 2019).

### 4.4.3. We have a good understanding of the reasons why women may choose not to participate in breast screening

Ackerson & Preston (2009) completed a systematic review of applied decision theory from economics and psychology to understand why some women with access to care do not seek cancer screening. The inclusion criteria included:

- qualitative or quantitative research design
- breast and/or cervical cancer screening as the primary health promoting behaviour (it is not clear whether the outcome was intention or participation, or both), and
- published between January 1994 and November 2008.

Forty-seven papers were initially identified, 19 of which met the inclusion criteria. Within these 19 papers, the authors recorded reasons for obtaining or not obtaining cancer screening and then organized the reasons into four relevant decision theory principles: emotions, Prospect Theory, optimism bias and framing. The authors did not appraise the quality of studies. None of the 19 papers were from Australia: we have included this paper in this literature review because it reflects themes identified in primary research about Australian women's views about breast cancer (namely fear). The role of fear has applicability to Australian women's screening choices.

The main findings of Ackerson & Preston's systematic review were that all women have fears and uncertainty, but the sources of their fears differ, resulting in two main decision scenarios:

- 1. Adherence to routine screening, which occurs when women fear cancer but trust care providers, seek knowledge, understand risk and frame routine care as the status quo, or
- 2. Non-adherence to routine screening, which occurs when women fear medical examinations, providers, tests and procedures, do not have or seek knowledge about risk and frame their current health as the status quo.

Ackerson & Preston reported that women from lower socioeconomic groups and minorities are much less likely to fear and mistrust healthcare providers and do not feel empowered to seek out information. They may not believe they are at risk for cancer and/or do not understand the effectiveness of early detection and treatment. Ackerson & Preston note these factors co-occur

and reinforce each other, producing a 'current health' status quo whereby women assume that they are healthy and do not go to a healthcare provider unless they feel very ill. In contrast, Ackerson & Preston reported that women from higher socioeconomic backgrounds with more traditional education often have access to high-quality healthcare, are given the time and attention of their healthcare providers (whom they trust) and are empowered to obtain information. As such they are more likely to see themselves at risk for cancer and understand the effectiveness of early detection and treatment. The authors noted these factors also dynamically co-occur producing an entirely different 'preventive health' status quo where women rely on their healthcare providers and on routine medical care for good health.

Ackerson & Preston reported on three common themes in the literature:

- 1. Women fear different things: this fear can drive adherence or non-adherence to participating in routine population-based breast screening
- 2. It will not happen to me: risk perception can promote or discourage screening participation (this links to concepts of fatalism/what will be will be), and
- 3. No one told me that I should: providing trusted health advice.

From the participation qualitative research (methodology described in *section 4.1.1.*), Blue Moon Research & Planning (2008) also articulated other potential barriers to participation and noted that these are often inter-related:

- Pain and discomfort associated with a mammogram (and fear of painful mammograms in the future), and a potential association with negative word of mouth
- Issues with service delivery (such as disengagement with primary care services) *NB* this issue was not articulated in other literature, but the way women were treated was a strong reason to not re-screen if they felt that they had had a negative experience and not been well-cared for or they had experienced considerable anxiety associated with recall to assessment for a final benign outcome and did not wish to repeat the experience (i.e., low acceptability of the benefits of participating in screening)
- Concern that the mammogram will have an adverse impact on their health, and
- Embarrassment associated with having breasts touched by another woman.

Other key themes identified in the literature included the role of a self-care or preventive health mindset, lack or/lower priority in busy/complex lives and the role of informed choice and the influence that women's understanding of the benefits and risks of participating in breast screening has on intention to screen and choice. As noted in the Blue Moon Research & Planning study (2008), these themes are likely to coexist within an individual woman's decision not to participate in screening.

Together, these themes provide a framework for discussing the other literature on Australian women's understanding of and attitudes towards participating on population-based screening. A pervasive view that no symptoms means no cancer is also a key driver for the choice to not participate in screening. For example, not having symptoms of breast cancer was noted by 19 percent of Cullerton et al.'s study participants as a reason for not participating in routine screening. Further research on this issue is discussed in *section 4.2*.

### **4.4.4.** Women fear different things: this fear can drive adherence or non-adherence to participating in routine population-based breast screening

Common themes reflected some of the findings on women's understanding of breast cancer and risk factors. These included that fear of cancer and/or beliefs such as fatalism underpinned

knowledge of and attitudes towards breast cancer, that silence around the disease is common (including that breast cancer is a disease that will not affect them) and that breast cancer is clearly symptomatic (findings which are similar to those discussed by Ackerson & Preston, 2009, see *section 4.1*).

### The influence of fear (of the mammogram itself, the outcome of screening, or exposure to radiation) and fatalism on women's choice to participate in breast screening

Ackerson & Preston (2009) noted fear prohibited preventive health care, supporting the 'current health' status quo. Seven studies showed women did not obtain breast screening because they feared screening would reveal cancer and they preferred not knowing. Additionally, the authors found evidence that even if women acknowledged that cancer screening was important to their health, fear influenced their decision not to have regular breast screening. Fear of breast cancer or of screening could be a barrier (three studies), with fear of radiation treatment being the greatest fear. However, Ackerson & Preston also found fear motivated routine screening:

...depending on the source of the fear, women could either be shown to avoid (when fearing the test or the result) or to seek (when fearing cancer itself) screening; in both cases, they acted to reduce the risk that was salient to them. Thus, consistent with decision theory, fear caused women to avoid risk, but the way in which they framed the risk, or the source of their fear, created opposing effects on behaviour.

Blue Moon Research & Planning (2008) (methodology described in *section 4.1.1.*) also noted that fear of results, concerns about pain during the exam, lack of understanding about the mammogram as a procedure (or the screening process more broadly) and fear of the results were cited as reasons for not participating in screening. These results related to lapsed and never-screeners, and they tend to consider that the benefits of mammography (as articulated in *section 4.1*) did not outweigh their concerns and fears. Other research commissioned by BreastScreen Australia programs (Essence, 2011) identified that under-screened women tended to have a fatalistic approach to breast cancer as well as fear of a result where cancer is detected and that this influenced their participation in regular screening.

#### The influence of fear on specific cohorts of Australian women

#### Aboriginal and Torres Strait Islander women

We discussed research describing Aboriginal and Torres Strait Islander women's fear and fatalistic beliefs about cancer (noting that fear of cancer is not restricted to this group of women alone). Shahid & Thompson (2009) included findings from the 2008 Australian Institute of Health and Welfare BreastScreen Australia Monitoring Report for 2004-2005, which showed the age-standardized participation rates for Aboriginal and Torres Strait Islander women aged 50-69 years (35.8 percent) was much lower that the non-Aboriginal and Torres Strait Islander women (55.9 percent).

A more recent systematic review of Indigenous women's knowledge and attitudes towards breast screening (Kolahdooz et al., 2014) reported on one study of Aboriginal women living in Western Australia (Shahid et al., 2009). Kolahdooz et al.'s review highlighted the importance of addressing fear and risk perception in driving adherence to routine screening recommendations. While most of the papers focused on Indigenous women in other countries, the Australian paper (Shahid et al., 2009) explored how Aboriginal women's beliefs and perceptions of cancer help understand screening choice (method described in *section 4.1.1*.). Shahid et al. noted that study participants were ambivalent about screening and its purpose and importance, which the authors believed reflected a fatalistic view of cancer itself, the fear of diagnosis of cancer and fear of the screening procedure itself. Fear of the procedure was also raised as a reason why participants in Cullerton et al.'s 2016 study did not choose to screen (study design described in *section 4.1*).

Shahid & Thompson's 2009 literature review of cancer and beliefs continues this theme:

Fear of death, fatalism, payback, shame and other spiritual and cultural issues are reported in the few qualitative studies examining Indigenous beliefs and understanding of cancer which undoubtedly influences participation in cancer screening and treatment.

Regarding Indigenous people's understanding of risk of cancer, [or risk of getting cancer], Shahid & Thompson described an Australian study by Prior (2005), which found the belief that "cancer is contagious" and can lead to "social and emotional isolation" for the person who has been diagnosed with the disease. Shahid & Thompson noted that such social stigma can create fear and deter people from not only accessing screening or early detection services, but also cancer treatments as it is a disease that is tainted by the alienation it causes. Treolar et al. (2013) (methodology described in *section 3.1.1* of this report) also reported that these misunderstandings about cancer acted as barriers to screening, treatment and support for Aboriginal and Torres Strait Islander women. In this study, fear of cancer was described as affecting numerous areas of the cancer prevention and care journey. For screening specifically, fear of cancer was described as preventing effective communication about the meanings and the use of screening tests. While the following quote was from an Aboriginal and Torres Strait Islander health worker demonstrating the difficulty in explaining cervical cancer screening in terms of detection of pre-cancerous cells, the quote also mentions fear of test results, a concept that Pilkington et al. also found:

And there's also that psychological barrier, that fear that ... if you get a problem with your test, it means you've got cancer. So there's room for education there in that this is a test looking for cells that could become cancer if you left them there.

Pilkington et al. (2017) found fear was the main reason for non-participation by Aboriginal and Torres Strait Islander women in screening in this study group, including both fear of the results of the mammogram combined with fatalistic beliefs about cancer and discomfort about the mammogram. Some of the Aboriginal participants in the Blue Moon research (2008) also noted the importance of cultural perceptions of breast cancer and the reluctance to between discuss women's business (like breasts and breast cancer) with men. This could contribute to a lower screening rates too if male partners were not supportive of screening.

#### CALD women

O'Hara et al. (2018) assessed the emotional, knowledge and structural barriers to breast screening, using three 'knowledge barriers to screening' belief statements and six 'emotional barriers to screening' statements were included in the screening survey. Study participants were CALD women living in Melbourne. The 'knowledge barriers to breast screening' belief statements were:

- Breast screening could reduce my chance of dying from breast cancer
- Breast cancer can often be cured, and
- It is recommended that women my age have a breast screen.

Of the six emotional barriers to breast screening belief statements, two were relevant to this literature review due to their link to fear. The statements were: 'I would not want to know if I

have cancer', and 'I put off a breast screen because I'm worried they might find cancer'. Among CALD women, health literacy was not associated with screening participation. Knowledge barriers were not associated with screening participation for any cultural group, but emotional barriers were found to be the most important barriers for up-to-date breast screening.

#### Fatalism: the role beliefs about the treatability of cancer plays in screening participation

Some participants in Pilkington et al.'s 2017 study noted that a fatalistic attitude can prevail in women with a family history of cancer who were often reluctant to have a mammogram because:

#### *they think they're going to get it* [cancer] *anyway.*

Other related myths about screening identified in the literature as reasons for not choosing to participate in population-based breast screening included belief that cancer is untreatable:

> 'it is useless because if something abnormal is found nothing can be done about it' (reported by four percent of participants in Cullerton et al.'s 2016 study).

Fatalism was also cited as a related reason for not participating: 'I will leave it for God to decide' (reported by two percent of participants in Cullerton et al.'s study). Keogh et al.'s 2011 study also discusses views about cancer inevitability and women's risk response to this (see section 4.1).

#### 4.4.5. It will not happen to me: risk perception can promote or discourage screening participation

Ackerson & Preston (2009) reported consistent evidence that women did not obtain screening because of misconceptions of their individual risk of cancer and the benefits of screening, thereby supporting the weighting function of Prospect Theory: "this is striking evidence of the optimism bias". Ackerson & Peterson noted evidence that indicated women who do not understand the risk/causes of cancer believe they are not at risk, assume they are healthy and do not perceive 'routine exams' as part of the status quo for maintaining health. The authors noted that beyond biases that may influence how a person processes information, many women simply do not have adequate information about cancer and screening. Additionally, the review found evidence of a misconception about the extent to which people can 'feel' or 'detect' cancer in their own bodies, with many women thinking that routine cancer screening is unnecessary because they take good care of themselves and do not experience symptoms. Women's views that it is not 'healthy' to look for breast cancer and that they feel well were also reasons cited in Blue Moon Research & Planning's 2008 research as reasons why women were never-screeners.

While not included under attitudes to breast screening in their paper, Cullerton et al. (2016) also collected data on reasons that CALD women did not participate in screening, with several of the statements being of relevance to risk perception. A common reason for women not having a mammogram before the education sessions reflected beliefs about risk, including not being at risk of developing breast cancer (19 percent). Cullerton et al. did not report women's reasons for not participating in cancer screening at the level of cultural group, but they made some overarching comments about the reasons cultural groups gave for not participating in cancer screening, some of which relate to the beliefs around perceived breast cancer risk. For example, study participants in the Bosnian group were more likely than other participants to select 'I don't feel at risk', 'fear of examination' and 'I don't have any symptoms' (along with Indian women for the third reason). Interestingly, Blue Moon Research & Planning (2008) noted that CALD women were more likely to not understand that screening is for well women, and they often cited the lack of symptoms as a reason for not participating in screening (but there also seemed to be

some confusion in the responses that screening is for asymptomatic women as one of the quotes noted that women do not participate in screening unless they feel a lump). This was also a reason for Aboriginal women not participating (i.e., they were asymptomatic at the time); breast self-exam was sufficient.

In their qualitative study (methodology described in *section 4.1*), Keogh et al. (2011) described risk perception and how it related to screening behaviour among women who have not had breast cancer but who are at increased but unexplained familial risk of breast cancer. Keogh et al. classified women into five groups based on risk perception and screening response to perceived risk. Risk management style considered what the women said about their risk, how they felt about their risk and what they said they did about their risk. The categories or 'risk management styles' are reported in *Table 7* (below) along with a description of the women's screening behaviour.

Group	Risk management style
Do not worry about cancer, but do screening	All claimed to routinely undergo screening (mammography, BSE and CBE) Some had yearly mammograms, others two-yearly All began having mammograms before age 50 years
Concerned about cancer risk, so do something	All had yearly mammograms before age 50 years Other strategies used to reduce risk (healthy lifestyle, reducing stress, BSE)
Concerned about cancer risk, so why don't I do anything?	All had had their first mammogram between 22 and 34 years but none had managed to continue with routine mammography
Cancer inevitable	Some had regular mammograms to detect cancer early, but others did not participate in screening due to the sense of fatalism
Cancer unlikely	One had mammograms, the other avoiding them if possible

 Table 7: Breast screening participation among women at increased but unexplained familial risk of breast cancer by risk perception group (Keogh et al., 2011)

Keogh et al. noted that during their analysis, women's personal or perceived risk could not be easily separated from their emotional response to their perceived risk or their practical response. As such they considered risk perception, the emotional response to risk perception and the practical response to risk perception to be interconnected and must be considered together. The five management styles and the findings on perceived risk for each of these styles that Keogh et al. identified from the interviews are included below. We have also included the women's descriptions of their perceived individual risk as this is the only paper we found that provided statements articulating Australian women's individual perception of their risk of breast cancer and the variation in individual risk perception.

#### Group 1: Don't worry about cancer risk, but do screening

All six women in this group had one or two-first-degree relatives diagnosed with breast cancer before aged 50 years. All could describe that intellectually they knew their risk was higher than

population risk due to their family history but claimed not worry about their breast cancer risk. Their description of their individual risk included:

> Same as most other people. More than 1 in 11. A fair bit higher than the population. A high risk of getting it.

#### Group 2: Concerned about cancer risk, so do something

The six women in this group were more comfortable expressing concern over their risk of breast cancer. Their description of their individual risk included:

Guess 50 percent. Up there. Not much higher than anyone else. Definitely higher risk.

#### Group 3: Concerned about cancer risk, so why don't I do anything?

The four women in this group also expressed concern about their risk of breast cancer due to their family history, but were reported to have asked themselves in the same breath 'why don't I do anything?' Their description of their individual risk included:

One in three.

High.

#### Group 4: Cancer inevitable

The five women in this group interpreted their family history as meaning they were going to get breast cancer and were convinced about the inevitability of breast cancer. Instead of being able to view breast cancer as an event with a level of probability attached to it, they apparently saw breast cancer as a certainty in their life. For two participants, Keogh et al. reported this certainty had the potential to lead to fatalism and the sense that nothing they did would make any difference. Their descriptions of their individual perceived risk of breast cancer included:

If I'm going to die its going to be of breast cancer.

Time bomb.

I got it into my head that I was going to get it.

#### Group 5: Cancer unlikely

Only two women were convinced they were not going to get breast cancer despite their family history. Both were apparently uneasy about sharing their risk perception, were reluctant to reveal their belief that they were not going to get cancer as, Keogh et al. noted the women appeared to understand that this was not a socially acceptable position for women with a strong family history of breast cancer. For both women their description of their individual risk of breast cancer was:

Do not think I will get it.

Related to this, are findings from the Blue Moon Research & Planning's participation qualitative study (2008), which found that family risk can be used as a reason for not participating in screening: women perceive that breast cancer is not going to affect them personally because

there is no family history. Blue Moon noted that these women were likely to undertake breast self-exam and consider this to be a sufficient form of screening.

#### 4.4.6. Health literacy and the impact of a self-care, preventive health mindset

Health literacy and women's mindset towards preventive health and self-care are likely to be significant drivers of whether a woman chooses to participate in routine breast screening. This theme was identified across a range observational studies and different cohorts of Australian women, as well as a key point identified in BreastScreen Australia program research into the reasons why women are under-screened (that is, preventive health care in the form of medical tests like breast screening is not a priority for some women).

When Kwok et al. (2012) examined the relationship between cultural beliefs and women's breast screening choices, there were no significant differences for the subscale 'Breast cancer knowledge and perception' and screening practices. Kwok et al. noted their findings supported previous research that knowledge of breast cancer does not associate with immigrant Chinese women's screening choices, whereas other related factors such as attitude towards health check-ups and perceived barriers to mammography may be influential.

Another factor explaining the low participation in breast screening by Aboriginal and Torres Strait Islander women, and a view commonly expressed by health professionals in Pilkington et al.'s 2017 study was women's lack of understanding about the issues related to breast cancer. The authors noted this finding was consistent with low levels of health literacy in relation to cancer generally among Aboriginal and Torres Strait Islander people. Lack of education on screening and the absence of cultural appropriateness in the BreastScreen Australia screening program were also identified as barriers to breast screening for Aboriginal and Torres Strait Islander women; however, Pilkington et al. noted that health education (not further defined) and group participation appeared to have influenced some women on the merits of screening with some feeling of obligation to participate, possibly as a result of the influence of others.

For Australian-Indian women (Kwok et al., 2015), the only significant relationship was between breast cancer knowledge and the performance of breast awareness practices. There was no significant relationship with mammography or clinical breast examination.

Blue Moon Research & Planning (2008) participation qualitative research also reflected on another dimension of self-care: women participating in the research noted that they knew about breast screening and its benefits but were time-poor or had complex lives (and enough to deal with in their day-to-day lives): they did not prioritise participation in screening (i.e., they did not place a premium on self-care). The authors noted that women did not have a high awareness of the BreastScreen program overall (which they thought reflected the level of priority these women gave it). This finding was common to never-screeners.

#### 4.4.7. No one told me that I should: providing trusted health advice

Regarding women being misinformed about their personal risk of cancer and their ability to detect it, Ackerson & Preston commented:

An unanticipated and disturbing theme in the literature was the fact that many reported that they were not told by their healthcare provider that they needed to obtain screening or were not told of the benefits and risks.

They cited six papers that showed that even when healthcare providers recommend participation in routine screening, sometimes women still do not obtain the test because they are uncertain about the provider's motives, particularly when the provider did not inform them

about the benefits and risks of screening. Further, the 2009 evaluation of the BreastScreen Australia program (2009) noted that Blue Moon Research + Planning's 2008) participation qualitative study found that GPs are effective channels for providing trusted advice on screening information, with GPs wanting more communications from BreastScreen Australia. The importance of receiving trusted advice from other trusted health professionals was also raised in relation to Aboriginal and Torres Strait Islander women. The Blue Moon research noted that limited information about screening benefit and risk was conveyed to Aboriginal women (most of the information provided being logistical in nature); however, the communications cascade (discussed in *section 4.5*) is an important factor in women's decision-making about participating in screening.

We identified also two articles on cancer screening choices among Australian Russian-speaking women: Andreeva & Pokhrel (2013); and Team et al. (2013), which provide insights into the theme of 'no-one told me I should'.

Andreeva & Pokhrel (2013) undertook a systematic review which aimed to synthesise the published research about breast screening of women originating from Eastern Europe and to identify potential psychosocial barriers towards breast screening specific to this population. The authors identified all observational, general population studies on breast screening with Eastern Europe immigrant women and without any country, language or age restrictions. Interventions included breast self-examination, clinical breast examination and screening by mammography. The authors selected 30 studies published between 1996 and 2013 including Team et al.'s 2013 study (also discussed further below). Study quality was assessed using a checklist adapted from quality assessment guidelines.

Regarding psychosocial barriers to screening choice, the authors found Eastern European immigrants exhibited low health-related self-efficacy, external locus of control, low health motivation, reliance on provider initiative regarding prevention, beliefs in the physician's responsibility for screening referral, lack of proactive preventive care history, and lack of knowledge about prevention. They noted one study that specifically assessed attitudes about improving prevention had reported that 47 percent of the relatively well-educated women in the sample had expressed the need for physician initiative. The authors in their discussion and conclusion noted that regardless of host country, healthcare access, or educational level, Eastern European immigrant women largely exhibited an external locus of control regarding health matters. They also remarked that Eastern European immigrants constitute a growing segment of multicultural societies and their older age, white race, inadequate engagement in prevention and low initiative in health matters puts them at increased risk of breast cancer, yet this population group has rarely been targeted by screening efforts.

Team et al. (2013) completed a small qualitative study, using in-depth interviews of eight women (mean age: 62 years; mean duration of 29 years residence in Australia). This study was included in Andreeva & Pokhrel's systematic review but is included here as more detail is useful. Team et al. noted that all women had grown up in the former Soviet Union, where health checks were compulsory. This had a profound effect on women's screening behaviours. As context, the authors noted that in the former Soviet Union, screening occurred without complementary health education of risk factors of cancer, the rationale for screening, or the value of health promotion. The women in Team et al.'s study continued to rely on health professionals to motivate them to undertake screening, regardless of their level of education or duration of residence in Australia. Women who presented for breast screening only once or infrequently explained they did so on the advice of health professionals or when they received a reminder from the screening service; none presented on their own initiative. Of the four women in the study who were in the recommended age for mammography, one attended regularly upon her

GP's advice, two attended occasionally upon their GP's advice and one had only had one mammogram.

Team et al. discussed that socialisation in relation to health and medical services in the former Soviet Union shapes Russian-speaking Australian women's access to and use of health services in Australia. Women in their study believed that health professionals and the health system are responsible for promoting their health. Additionally, these women who had emigrated from the former Soviet Union did not appear to regard the promotion of breast screening as relevant to them. In their discussion, the authors noted that some participants, while knowing about cancer risks (not further defined) and being familiar with early diagnosis and prevention measures, did not attend screening because they lacked specific information on when and where this was available, took no initiative to find this out and depended on their GPs for advice.

#### 4.4.8. Women do not understand the need for regular screening

Blue Moon Research & Planning (2008) undertook participation qualitative research (methodology described in *section 4.1.1*), which reported misunderstandings about the need for regular screening (i.e., some research participants knowledge of this resulted in their thinking that an 'all clear' result meant that they did not have breast cancer and did not need to continue to participate). Some groups of women involved in this research also reported that they did not consider breast cancer to be an issue for them

### 4.4.9. Social influences: the impact of women's awareness of breast cancer on participation in breast screening

The 2009 evaluation the BreastScreen Australia program (BreastScreen Australia, 2009) reported on the influence of celebrities with breast cancer on women's intention to screen, noting that media coverage can increase women's awareness of screening and positively influence their choice to participate, including increasing younger women's awareness of breast cancer (and health seeking choices relating to participating in screening, the so-called 'Kylie Minogue' effect). While reported data focused on increases in women aged 40 to 49 years, no information on this influence was provided for women aged 50 to 74 years.

Pilkington et al.'s 2017 qualitative study of the perspectives of Aboriginal and Torres Strait Islander women on participation in mammographic screening in Western Australia (methodology described in *section 3.1.1* of this report) explored factors that impacted on participation in breast screening. Aboriginal and Torres Strait Islander women in this study were reported as generally willing to have a screening mammogram. One of the key reasons given for engaging in breast screening was the women's recognition of increased risk of breast cancer in the context of having a family history to breast cancer. Most of the study participants (53 of the 65) had had a mammogram, with many having had their first mammogram before the age of 50 years.

### **4.4.10.** Body image and being touched by strangers: some evidence suggests that privacy and shame may act as barriers to participation in screening

Both Pilkington et al. (2017) and Shahid et al. (2009) identified shame as a barrier to screening among Aboriginal and Torres Strait Islander women. In Pilkington et al.'s study, many Aboriginal and Torres Strait Islander women were reluctant to talk about breast cancer. For some, selfexamination was seen as daunting. Being touched by others was also an issue raised in Pilkington et al.'s 2017 study and women feared having to show their breasts to another woman. This fear being highlighted by women as a significant barrier impeding participation in breast screening. Related to this is the concept of shame as a component in screening decision-making, which Shahid et al. (2009) explored. They also reported that a reason for Aboriginal women's lower participation in screening may relate to feelings of shame associated with being touched by another person in a private body part. While the authors provided lessons for health, these focused on cancer treatment. Findings from Shahid et al.'s 2009 paper about Aboriginal people's views of cancer are discussed in *section 4.1.1* of this report.

This theme of not discussing breast cancer because of embarrassment or shame was not restricted to Aboriginal and Torres Strait Islander women as this was also a finding among Chinese-Australian women (Kwok et al., 2011) and Indian-Australian women (Kwok et al., 2015). Kwok et al. (2015) proposed a possible reason for the high level of breast awareness among Indian-Australian women was due to this being a common and simple practice compared with CBE or mammography, as it does not involve issues including being touched by others. Being touched by others is an issue that Kwok et al. (2015) noted had been found in previous research to be a barrier preventing many Indian women, even those equipped with a good knowledge of breast cancer prevention measures from attending screening services. Ogunsiji et al. (2017) also noted Australian-African women's negative attitudes towards discussing and touching breasts. Regarding the relationship between cultural beliefs and migrant African women's screening choices there were no significant relationships found between knowledge and perceptions about breast cancer and breast awareness, clinical breast examination or mammography; only that the concept of having regular health check-ups has a significant impact on which women did or did not have clinical breast examinations as recommended.

Blue Moon Research & Planning (2008) also summarized barriers to participating in screening for Aboriginal and Torres Strait Islander and CALD women and reported that some factors related to having the mammogram: embarrassment or discomfort associated with showing their breasts or being touched by a stranger.

# 4.4.11. When information on overdiagnosis/over-treatment is provided, screening attitudes remain largely positive but women's attitudes to participating in mammography can change with more women choosing not to participate

Jansen & Houssami (2018) reported that women may be sceptical of information about overdiagnosis and be concerned that this information might be used to provide fewer screening services. This is discussed further in *section 4.5*.

Hersh et al. (2015) conducted a randomized controlled trial of 419 Australian women using a decision aid including information about over-detection to support informed choice about breast screening (methodology and other baseline knowledge results are described in *section 3.1.2* and *section 3.2*). At baseline, women's basic conceptual knowledge and attitudes in both study groups were similar, screening attitudes were positive overall and most women (90 percent) indicated they definitely would or were likely to have breast screening in the next few years. After the decision aids were administered, the attitudes of women in the intervention group to breast screening remained positive overall compared with women in the control group; however, significantly fewer women in the intervention group expressed positive attitudes towards breast screening. For the control group, 83 percent (304/408) of women met the threshold for a positive attitude towards screening, whereas for the women in the intervention group, only 69 percent (282/409 women) met the threshold (*p*<.0001). Slightly fewer women answered the attitude questions which accounts for the difference in the denominator compared with other results reported.

Similarly, women's screening intention remained positive in both groups after the decision aids were administered, but significantly fewer women in the intervention group (74 percent, 308/419) intended to be screened compared with women in the control group (87 percent, 363/419), (*p*<.0001). When the authors analyzed the women's responses for informed choice and its component variables of knowledge, attitudes and intentions, significantly more women (24 percent, 99/409) in the intervention group were judged to have made an informed choice about breast screening than women in the control group (15 percent, 63/408) (difference nine percent, 95%CI 3-14; *p*=.0017).

In Hersch et al.'s 2013 study on Australian women's views on overdiagnosis in breast screening, women's prior awareness of breast cancer overdiagnosis was minimal with women generally reacting with surprise at the concept. This focus group-based study included a presentation explaining overdiagnosis, incorporating different published estimates of its rate (1-10 percent, 30 percent, 50 percent) and information on the mortality benefit of screening. The objective was to elicit women's responses to information about the nature and extent of overdiagnosis in screening mammography and to explore how awareness of overdiagnosis might influence attitudes and intentions about screening. Women's responses to overdiagnosis and the different estimates of its magnitude were diverse (Hersch et al., 2013). A few participants who were mainly younger and had limited screening experience determined the possibility of overdiagnosis and over-treatment as a 'distinctly negative, off-putting factor in the screening 'equation'.

The lower and intermediate rates had little impact on women's attitudes and intentions to screen. For the 1-10 percent estimate, women generally perceived this as negligible or nothing to worry about and it tended to confirm women's confidence in screening. Similarly, at the 30 percent estimate most women found this level of overdiagnosis acceptable, considered it to be outweighed by the possible benefits of early detection and had limited impact on women's existing views and screening intentions; however, at the 50 percent overdiagnosis estimate, some women perceived a need for more careful decision-making about screening.

Women's behavioural responses to this rate were quite diverse. Some women reconsidered whether screening was likely to be worthwhile for them personally given their own perceived risk factors for breast cancer including family history, breast feeding, use of the oral contraceptive pill, breast self-examination, lifestyle and stress and discussions suggested that some women might decline screening altogether. For other women, this knowledge did not at all affect their feelings that breast screening was worthwhile, with a few women declaring they would still participate in screening even if the over-detection risk was higher than 50 percent. In essence, the authors suggested the higher rate would affect women's decision-making process even if it might not change women's choice.

Hersch et al.'s 2013 study also elicited a relationship between previous screening attendance and the extent to which information appeared to influence women's perceptions of breast screening: regular screeners tended not to alter their positive screening intentions after learning about overdiagnosis. In contrast, women with less screening experience appeared more concerned about the issue.

Hersch et al. (2017) investigated the use of a decision aid that included information on overdetection to support informed choice about breast screening. The authors examined a series of potential mediators (knowledge about over-detection, worry about breast cancer, attitudes to breast screening and anticipated regret) to explore causal pathways between exposure to information about over-detection and subsequent breast screening intentions. The authors reported the relationship between exposure to information on over-detection and women's subsequent breast screening intentions was mediated by multiple cognitive and affective pathways. Specifically, the intervention decision aid had substantially improved women's understanding of over-detection, and it influenced women's attitudes towards having screening both directly and indirectly via its effect on knowledge.

Regarding the mediation analysis, the authors reported this revealed that:

these mechanisms involving knowledge and attitudes were particularly important in determining intentions about screening participation.

Additionally, anticipated regret was reported to play a role in several additional pathways linking knowledge, attitudes and intentions:

as more women became more knowledgeable about over-detection and their screening attitudes became less positive, this lessened their expectation that not screening would cause regret and increased the realisation that screening might cause regret, which influenced intentions.

Hersch et al. (2017) noted their mediation findings were in line with the explanatory account of health decisions offered by the theory of planned behaviour whereby attitudes towards a behaviour are determined by salient beliefs about its consequences (noting that in this case the understanding conveyed by the decision aid that over-detection is a possible consequence of screening), with these attitudes determining intentions. The authors also noted their observed mediation effects involving anticipated regret accorded with other evidence supporting its usefulness as an extension to the theory of planned behaviour but that worry about the threat of breast cancer did not appear to play a major role in determining screening intentions in their study participants. The authors concluded that while they had previously shown that giving women evidence-based information about over-detection in breast screening can change women's screening intentions, they had, for the first time, provided evidence through mediation analysis about how this cognitive and affective process works; that is, the decision aid intervention achieved substantial knowledge gains and thereby influenced attitudes and intentions towards screening.

#### 4.5. How women would like to be informed about the risk of breast cancer and the benefits and risks associated with participation in a populationbased screening program

*Section 4.5* of this report describes the findings presented in published, peer-reviewed literature and grey literature for research question 3:

How would women like to be informed about the risk of breast cancer and the benefits and risks associated with participation in an organized breast screening program?

The papers discussed in this section of the literature review are listed below.

#### Systematic review

Two systematic reviews: Peterson et al., 2016; Edwards et al., 2013

#### Literature review

Five reviews: Jansen & Houssami, 2018; Hersch et al., 2018; Forbes & Ramirez, 2014(a,b); Shahid & Thompson, 2009
#### **Observational studies**

11 studies: Pilkington et al., 2017; Cullerton et al., 2016; Ghanouni et al., 2016; Robinson et al., 2015; Hersch et al., 2013; Pappadis et al., 2013; Treolar et al., 2013; Browne & Chan, 2012; Barratt & McKenna, 2011; Kwok et al., 2011; Shahid et al., 2009

#### **Grey literature**

Four papers: BreastScreen Australia, 2019; Open Mind, 2012; Essence, 2011; Blue Moon, 2008.

#### **Key findings**

We know very little about the range of information Australian women want to know or how they want to be informed about breast cancer risks and population-based breast screening. We do know that providing education to women on breast cancer, risk factors and breast screening can increase knowledge, reduce misperceptions about cancer and increase participation in population-based breast screening. We also learnt that many women want full, balanced information on screening, including issues associated with overdiagnosis/over-detection but other women may be more concerned that changing the 'pro' screening message to include more balanced information could result in confusion. Key messages could potentially focus on describing:

- mammography as a test and how the procedure will be implemented
- breast cancer incidence and that breast screening saves lives through early detection and wider treatment options/choices
- risk factors and what is known (especially regarding increasing age and why screening is most appropriate for women aged over 50 years)
- including information about overdiagnosis/over-treatment but also acknowledging what we do not know (i.e., that screening fids some cancers that would never cause harm, but we do not know which ones, so we treat everything and we are working to better identify non-harmful lesions), and
- present statistical data in icon arrays.

Importantly, all communications need to be delivered in a way that is culturally safe and competent. Aboriginal and Torres Strait Islander women want more information on breast cancer including its meaning and signs/symptoms to enable them to engage in screening, and that education delivered by local Aboriginal and Torres Strait Islander women who are well-regarded in the community and preferably who have personal experience of cancer would likely have an impact on screening participation.

Having a cascade of communications approaches and multiple touchpoints enables women to engage with content as they need, including simple overview messaging and more detailed evidence reviews. Ideally, this information is delivered by trusted advisors who have considered the reasons why women participate in screening (or do not) so that content can be more personalized to the woman reading it.

Blue Moon Research & Planning (2008) noted that research participants had a low awareness of informed consent, with few noting understanding that they had been asked to provide informed consent. It is unclear how this finding relates to Australian women today. Within the parameters of this literature review, we found only four observational studies that reported women's views on how they would like to be informed about breast cancer risks and the benefits and risks of

participating in breast screening. These studies included the views of Aboriginal and Torres Strait Islander women and of women who were included in a study about over-detection in population-based breast screening.

# 4.5.1. Providing education to women on breast cancer and breast screening can increase knowledge, reduce misperceptions about cancer and increase participation in mammography

Obviously, participating in specific education about breast screening increases women's knowledge of screening, and they can then use this information to determine whether they participate in screening. This finding is reflected in the following qualitative observational studies.

Cullerton et al. (2016) (methodology described in *section 3.1.1* of this report) found that following the intervention, significantly more women were able to identify the age at which breast screening should commence (14.8 percent pre-session vs 37.7 percent post-session; p=.003) and the correct frequency for breast screening (39.3 percent pre-session vs 90.2 percent post-session; p=.010). The authors noted the marked increase in knowledge about the recommended ages at which screening should take place was important since knowledge is a precursor for changes in attitudes and screening intentions. Further, following the education sessions, of the five attitude questions about breast cancer and breast screening the only significant increase found was among participants (towards strongly agree) in the attitude that screening would help put women's minds at ease regarding breast cancer (median pre-education session rating 7.0 (6.0-7.0); median post-education session rating 7.0. (6.0-7.0); p=.030).

Cullerton et al. (2016) found that while women's knowledge increased and women's attitude that screening would help put women's minds at ease regarding breast cancer became more positive, there was no change in reported screening behaviour, with the same proportion of eligible women (defined as aged 40 years and older) reporting they had undergone a mammogram pre- and post-education session (46 percent; *p=1*). The authors noted that none of the Samoan or Pacific Islander participants reported having a mammogram, consistent with the fact that they were all under 30 years of age. Prior to the education session, 30 percent of women from Bosnia, 33 percent from India, 40 percent from Spanish-speaking countries, 78 percent from Arabic-speaking countries, and 43 percent from Samoa and Pacific Islanders reported they intended to have a mammogram in the following 12 months. However, after the education sessions, more (not further defined) Arabic-speaking women, but fewer (not further defined) Bosnian, Spanish-speaking, Indian, and Samoan and Pacific Islander women planned to have a mammogram in the next 12 months, due apparently to increased knowledge about the target age range for breast screening and the younger age group of the participants (the age group breakdown for breast screening education participants was not given).

In Kwok et al.'s 2011 study, the 37 Chinese-Australian study participants attended a one-day educational session on breast health and breast screening, were given an information kit to take home, and attended a half-day follow-up session six weeks later. We have previously reported the pre-program or baseline findings on women's beliefs about breast cancer (*section 3.1.1* and *section 3.1.2*). Kwok et al. found the program increased the women's knowledge of breast health, decreased misperceptions about breast cancer and enhanced women's readiness to discuss these topics with other Chinese-Australian women. After the program:

• more women disagreed with the belief that having small breasts meant a lower risk of breast cancer (92 percent post-intervention compared to 73 percent pre-intervention)

- more women disagreed with the belief that:
  - feeling well meant there was no reason to worry about developing breast cancer
     (92 percent post-intervention compared to 84 percent pre-intervention)
  - a lack of symptoms was no reason to worry (87 percent post-intervention compared to vs 54 percent pre-intervention), and
  - thinking about breast cancer will cause it to happen (84 percent postintervention compared to 78 percent pre-intervention).

The impact of women's increased knowledge of breast health and decreased misperceptions about breast cancer on awareness of and participation in breast screening was mostly positive. Most women (87 percent) reported that they were aware of mammography prior to the program; after the program, this increased to 92 percent of the women. The largest increase in women's knowledge of preventive health practices was in how to perform breast selfexamination, with less than half (43 percent) of women reporting they were aware of how to perform this practice before the program, whereas 73 percent reported they knew how to do breast self-examination after the program. The program had a positive impact on self-reported mammography participation and intention to participate in mammography among the 15 women (41 percent of program participants) who were interviewed after the follow-up session, with 12 being over 50 years and in the eligible group for regular mammography and clinical breast examination. Of the 12 women, six had regular mammograms before the program and all indicated their intention to continue with regular mammograms. The program appeared to motivate the six women in the target age group who had never had a mammogram to participate as fur reported having one after the program and two expressed their intention to get one in the near future. For a very small number of women, the program either did not change their beliefs or led to negative changes in their beliefs about early detection, disease mortality and impact of thinking about breast cancer.

#### 4.5.2. What could information about breast screening include?

Barratt & McKenna (2011) reviewed in-consultation discussions about breast screening in the American context, noting that there were some principles that should be followed when discussing screening decision-making in primary care. Key principles included describing the test and its sensitivity/specificity and what this means to patients and potential complications. This information needs to be presented in a way that is easily understood. They talk about several different ways of presenting this information:

- Descriptive: "mammography is the best screening test but there may be more harm than benefit from screening women younger than 50 years"
- Conventional, which has a strong focus on presenting statistical information to women (such as "reduce mortality by 15-20 percent; reduce your absolute chance of dying of breast cancer by 0.05 percent over ten years, etc.")
- Natural frequency: "Without screening, approximately 30 of 1,000 women over age 40 can be expected to die from breast cancer. With regular mammography, six lives will be prolonged, so only 24 women will die of breast cancer. However, regular screening those 1,000 women will lead to more than 2,000 false positives results, and 150 women will receive unnecessary biopsies."

Barratt & McKenna focused on in-consultation communications; however, much of BreastScreen Australia's communications occur at a population level. Communications messages were identified in the Blue Moon Research & Planning study (2008): that is, women thought motivating messages focused on telling women that she does not need to have a family history to be at risk of breast cancer, that it is a common cancer, that only a small number of women recalled to assessment will have breast cancer, why compression is necessary and BreastScreen Australia eligibility criteria. These messages were similar to those identified in BreastScreen Australia research about under-screened women's preferences (Essence, 2011). That is, women want information about:

- Breast cancer incidence (to ensure women understand that this is a common cancer among women and that family history is not a prerequisite to developing breast cancer)
- That early detection increases treatment options and survivability (to challenge views that nothing can be done if breast cancer is diagnosed), and
- Age: most women are aged over 50 years when diagnosed with breast cancer.

While broader than breast screening alone, Edwards et al. (2013) completed a Cochrane review looking at the role of personalized risk communications in increasing informed decision-making for screening. The systematic review covered 41 studies with 28,700 participants. Edwards et al. concluded that providing risk information that is personalized can improve informed decision-making. Included studies focused on providing personalized risk advice based on:

- use of a risk calculator such as an individualized GAIL or Claus score
- family history (defined as one or more first degree relatives diagnosed with breast cancer before aged 50 years)
- age, and
- level of worry about developing breast cancer.

Risk advice was delivered in a number of ways including via information sheet, telephone conversation.

#### 4.5.3. Key messages about overdiagnosis/overtreatment

Hersch et al. (2018) and Forbes & Ramirez (2014a) both specifically discussed communicating the benefits and harms of screening with Australian women at the population-level. Hersch et al. (2018) reviewed provided a strong overview of practices relating to improving communication and decision-making about breast screening participation with a focus on informed choice. Key principles discussed in their review were:

- That breast screening is generally well supported by women: it is seen as the right thing to do (taking responsibility for health, social obligation, and feeling reassured)
- That there is a need to balance informed decision-making with a drive to increase participation leads to persuasive messaging (overly positive and simplistic messages can be problematic but are common)
- That informed choice means ensuring a woman has adequate knowledge, and screening intention and practice is consistent
- That any decision aids need to include balanced information about reasonable options and support accuracy of risk perception and value concordant decisions (i.e., a positive attitude to screening coupled with screening participation of intention to screen), and
- Accepting that advice includes information about overdiagnosis, which might lead to more women choosing to not participate in screening.

Forbes & Ramirez (2014a,b) reported on the approach used by the National Health Service (United Kingdom) to facilitate informed choice about screening, with a focus on articulating overdiagnosis issues. This approach was based on a Citizen Jury model, where British women contributed to developing the information that they thought was important to receive. Tailoring information to support informed choice involved describing overdiagnosis. Specific messaging from the NHS Citizen Jury (described in both Forbes & Ramirez' 2014 papers) including describing:

- lives saved (not deaths prevented):
  - i.e., screening saves one life from breast cancer for every 200 women screened (1,300 women per annum in the United Kingdom who do not die each year)
- benefits and harms in relation to the number of women who attend for screening (not the cohort of women who are invited) *NB comments on presenting this information also noted that benefits and harms should be presented next to each other (text and images like icon arrays, not graphs) to make it easier to see, assess and relate*
- overdiagnosis in a simple way (but not using the term overdiagnosis)
  - i.e., screening will find some cancers that would never have caused a woman harm
  - i.e., some women might receive more treatment than is needed to effectively treat or manage the findings from an abnormal screen
- providing simple information on magnitude of potential overdiagnosis
  - i.e., about three in every 200 women screened every three years from age 50 years, or 4000 women per annum will be offered treatment that they do not need
  - i.e., for every woman whose life is saved, three women are diagnosed with a cancer that would never have become life-threatening, and
- the state of current research and where uncertainty exists.

Hersch et al.'s 2013 qualitative study on women's views on overdiagnosis in breast screening (methodology described in *section 3.2.1*) gathered information on women's personal preferences regarding screening information and on providing information on breast screening to the community. Women expressed a range of personal preferences about the information they wanted and how they wanted to receive it:

- For some women, it did not matter whether they had information on over-detection as it would not make any difference to their own screening views or choices.
- Other women wanted to know about overdiagnosis to be able to make an informed choice about screening.
- Some women thought that making decisions was more difficult when faced with a lot of information or if they lacked confidence in their ability to understand numerical information (such as the chances of experiencing benefit or harm from screening): they often preferred to trust recommendations from their doctor or the government.

Many women favoured being encouraged to screen, some preferred to be given balanced information and left to make an individual choice, and some women endorsed both approaches.

Women in Hersch et al.'s 2013 study also held diverse views on how to effectively provide information on screening to the community. While many women favoured full, balanced information as the most ethical approach to communicating about screening, some argued that

up-to-date information about over-detection should be more widely available. This included women who remained positive towards screening. Other women felt that changing the conventional pro-screening message to include more balanced information could "*unleash widespread public confusion*". Some women who were personally not put off by the overdiagnosis information were concerned that it would dissuade others from screening.

A minority of women had more extreme views and suggested that information on overdiagnosis should be provided to women only <u>and</u> if they were diagnosed with breast cancer rather than before screening; however, other women suggested that the amount of information women required before screening would vary according to personal preferences and that this variation should be accommodated somehow.

The type of information provided and the baseline understanding of overdiagnosis as an issue was raised by Jansen & Houssami, who cited an American study of semi-structured interviews with 59 women aged 70 years and older; none of the participants had a history of breast cancer (Pappadis et al., 2018). Women given the same information about overdiagnosis developed by Hersch et al. (2013) (see *section 4.2*). Most women had a poor understanding of this concept initially (only a few had heard of it) and only limited information was provided about overdiagnosis. After information was given, of those who understood the information, 37 percent were likely to continue screening compared to 62 percent who did not understand the information provided. Jansen & Houssami suggested that in order to achieve an increase in knowledge about overdiagnosis (and a measurable level of 'informed'), more than brief information about this is needed. Communications about overdiagnosis need to consider the following:

- Providing more information about overdiagnosis could lead to confusion about or distrust in a screening program (or in health authorities who may be seen to be trying to use overdiagnosis as a reason to cut services) or could lead to unnecessary fear for women participating in regular screening balanced with
- Respect for women's intelligence and right to make an informed decision about undergoing mammography and (potentially) harmful and unnecessary treatment.

#### 4.5.4. Culturally safe, competent and appropriate communications

While focused on service delivery, Shahid et al. (2009) noted key lessons for health professionals in terms of delivering cancer services for Aboriginal and Torres Strait Islander women which also have applicability for communicating with women about breast screening. This includes:

- Recognising cultural diversity: 'not everyone has a strong understanding of the biological processes underpinning disease; some cultures have more traditional understandings of causation that are based in tradition and superstition': recognising this difference in when developing communications approaches may help to identify and dispel myths, and present facts in an appropriate cultural context
- 'Understand and consider that an Aboriginal patient might have different perspectives towards disease and treatment than a Western-trained doctor, and respect their right to participate in their own care': women in the communications audience should be involved in the development of resources, and
- *'Respect Aboriginal people and culture and show concern for the wellbeing of Aboriginal clients by seeking out and participating in cultural safety training and acting upon it Encourage other colleagues and service staff to do the same'.*

Delivering information contextualise to women's cultural background and health literacy levels was an important finding from the Ophelia project (2019). Multiple avenues and thoughtful, collaborative and codesigned interventions are likely to yield the greatest success in engaging with women. In this study, the authors developed five interventions which were found to be useful in engaging under-screened women in services:

- 1. communications sent/made in the woman's first language including information about the screening process (reach-out phone calls in a first language were highly effective at encouraging women to re-screen)
- 2. staff training in cultural awareness to increase staff confidence in providing culturally safe and appropriate care
- 3. peer educators in the community to engage women to screen
- 4. engagement in pharmacies where women can receive information from a trusted source in a familiar health setting, and
- 5. the provision of shawls with Aboriginal artwork, which increased Aboriginal women's comfort with the services provided.

#### 4.5.5. The importance of the communications cascade and multiple touchpoints

The National Accreditation Standards (BreastScreen Australia, 2019) recommends that *'information be provided in a form and manner that help patients understand the problem and treatment options available, and that are appropriate to the person's circumstances, personality, expectations, fears, beliefs, values and cultural background'.* Effective communications with women therefore require a range of different approaches designed to be suitable to the recipient of the information. Some grey literature identified as part of this literature review also focused on the importance of a communications cascade with multiple touchpoints in supporting a women's decision-making journey. Blue Moon Research & Planning (2008) reported findings from qualitative research noting a hierarchy of decision-making with regard to participating in screening:

- Awareness of breast cancer as a serious but potentially treatable illness
- The relevance and importance of breast screening as a means to detect cancer early and an appreciation of the balance of benefits and harms (i.e., information to enable informed decision-making)
- Advice on eligibility and invitations to participate and attend screening at regular intervals
- A physical presence (eg, a mobile unit or fixed clinic) that women perceive to be accessible, and
- Delivery of a service that meets women's needs.

Blue Moon Research & Planning (2008) noted the importance of having clear communications strategies targeted to different audiences and which consider each element that a woman uses to decide whether she will participate in screening. As noted in the 2009 evaluation of the BreastScreen Australia program (BreastScreen Australia, 2009), this means communications:

should include Program-wide and jurisdiction-based marketing, including materials targeted at specific audiences, GPs and community health workers such as Aboriginal and Torres Strait Islander health workers.

That said, the remaining research identified on this topic explored a range of different ways of communicating effectively with women, including assessing what their preferences were as well as the reasons why they are non/under-screened in the first place (i.e., depending on the results of segmentation). This includes:

- Delivery of 'talking' information via trusted champions and well-regarded people in the women's communities
- Segmenting the reasons why women are under-screened and responding accordingly, and
- The role of social media.

#### 4.5.6. Women respond to information delivered by trusted advisors

In 2016, Peterson et al. undertook a systematic review looking at patient-provider communications relating to cancer screening (including breast screening). PRISMA guidelines were followed. Included papers were published between 1992 and 2016, and included 35 articles, ten of which focused on breast screening (most of which were from the United States) No Australian papers were included in this systematic review. Bearing in mind that the way health care is delivered in the United States differs significantly from service provision in Australia, Peterson et al. reported some findings that are likely to resonate with Australian doctors and women. In relation to breast screening, the authors reported that a recommendation from a trusted provider to attend for screening significantly increases participation rates. In some included studies (Magai et al., 2004) the OR for participation for women whose doctor recommended screening was 2.29; 95%CI: 1.42-3.69; another study (Roman et al., 2014) noted that without a doctor's recommendation to screen, women were less likely to attend for screening (but there were some cultural differences with results not being significant for Black women). Common themes included that adherence was increased by talking about breast screening with enthusiasm and endorsement of screening programs and recommending appropriate tests, clear explanations about barriers and responsiveness to women's concerns.

# For Aboriginal and Torres Strait Islander women, more information on breast cancer delivered verbally by well-regarded local Aboriginal and Torres Strait Islander women may have a positive impact on screening participation

We previously have previously described a literature review by Shahid & Thompson (2009) and two observational studies by Pilkington et al. (2017) and Treolar et al. (2013) (see *section 3.1.1* for a description of the methodology), which identified lack of understanding and misunderstandings of cancer along with fear and destiny/fatalistic beliefs about cancer were common among Aboriginal and Torres Strait Islander women and contributed to lower participation in screening. These studies also included findings about what information on cancer Aboriginal and Torres Strait Islander women want and suggest ways that such information could be best delivered.

Pilkington et al. (2017) studied the perspectives of Aboriginal and Torres Strait Islander women on participation in population-based breast screening. Regarding education, the authors reported that participants in metropolitan and rural (but not remote) areas considered that increased education on breast cancer and on the importance of screening and early diagnosis is key to increasing screening participation. Participants without a health background emphasised the importance of publicising the work of BreastScreen WA, including explaining the mammography procedure and the wider screening process in ways that are respectful of cultural differences.

Pilkington et al.'s study participants also suggested that information be disseminated in groups via having a "yarn", with one-on-one sessions available for those who were not comfortable discussing breast cancer and screening openly. The authors reported their study had found that local Aboriginal and Torres Strait Islander women who are well-regarded in the community, and preferably those who have personal experience of cancer (including those who have endured tests, treatment and experienced the resulting emotions) should carry out education. These women were regarded by participants as more powerful and may be more likely to have an impact on screening participation.

Aboriginal and Torres Strait Islander women consumers also wanted to have support from another Aboriginal and Torres Strait Islander woman or women (block bookings were suggested) before, during and after the screening. Being accompanied was suggested as facilitating participation. Women in metropolitan and rural locations also suggested education and support could be more formalized by having more Aboriginal and Torres Strait Islander health workers providing community education, encouraging women to go for screening and talking them through the screening process.

In Treolar et al.'s 2013 qualitative study of Aboriginal and Torres Strait Islander patients, carers and their health workers, the majority of participants expressed a need for increased information to be provided to Aboriginal and Torres Strait Islander communities about cancer. Specifically, participants wanted information that facilitated community members' awareness of cancer including its meaning and signs/symptoms to enable them to engage in screening and prepare for possible diagnosis and treatment. Study participants were reported to have drawn on other education programs they were aware of, but typically stated that they knew of few or no programs for cancer education. They also expressed a need for cancer education programs at a number of levels (including for community members and for health workers). To illustrate the few or no resources provided on cancer for Aboriginal and Torres Strait Islander communities, a non-Aboriginal and Torres Strait Islander health worker was quoted as saying:

> It would be good to have more info, more widespread information about cancer. We've got so much health promotion brochures on 'What's Diabetes' or 'What does Speed or Cocaine do to the body?' you know all those kind of ... but there's nothing ... I don't think I've seen one thing on what cancer does to the body or what you can do, or what causes cancer, those kind of... health promotion materials would be useful.

#### Mother-daughter communication

Browne & Chan (2012) considered whether communication between daughters and mothers impacted on preferred ways to receive information about mammography. The authors interviewed eight mother-daughter dyads from NSW. Mothers were aged 50 to 66 years; daughters were aged 18 to 39 years. All were Anglo-Australian and only one study participant (a mother) had previously had breast cancer. Seven of the pairs discussed mammography, with the mother initiating the conversation for the purposes of information sharing (i.e., I have gone for a mammogram) or providing support (i.e., a daughter had found a breast lump). The authors reported that mothers positively influence their daughters' attitudes towards health-seeking behaviours and, like Aboriginal and Torres Strait Islander women, receiving information from a 'trusted' person known to the individual can be influential. Upward communication from daughters to mothers was thought to be a viable strategy to promote participation in breast screening.

#### **Other trusted sources**

Essence (2011) presented research participants with five ads designed to encourage women to participate in screening. Women were not as supportive of testimonial, humorous, or semi-factual story-telling approaches; however, they were more supportive of advertisements that included clear, direct and factual (and no-nonsense) information delivered by a familiar and trusted source. The second strategy favoured by women participating in this research was based on 'shock' value, which the authors thought would be useful in both engaging women with key facts about breast cancer and screening, but also galvanising under-screened women to make an appointment to be screened. It is also important to note that different tactics are likely to be more (or less) influential depending on the reasons why women choose not to participate in breast screening.

### **4.5.7.** Segmenting women's reasons for not or under-screening and responding accordingly

Several BreastScreen Australia programs have completed segmentation research in order to better understand why women do not participate in breast screening regularly (or at all), and to better understand how to respond in an effective way that might galvanise under-screened women to participate (Essence, 2011; Open Mind, 2012). Some of the possible approaches are summarized in *Table 8* (overleaf).

Reason for not screening	Potential communications approach/messaging
Too busy/not a priority (likely to be the largest group of under- screened women = ~70%)	More likely to agree that early detection saves lives, to understand the benefits of mammography, to agree that the benefits outweigh the negatives Provide advice on incidence and seriousness and that the procedure/access is quick Multiple, consistent reach-outs and reminders to encourage prioritisation (saturation via television, SMS, letters, etc. is likely to work)
Prefer to manage own health/distrust of Western medicine ( <i>likely to be the second largest group of</i> <i>under-screened women = ~20%</i> )	More likely to not prioritise having a mammogram, to hold fatalistic beliefs about getting cancer and to feel like screening is tempting fate Provide advice on survivability (you can have <u>control</u> over this, and early detection might mean that less treatment/more options) Multiple, consistent reach-outs and reminders to encourage prioritisation (saturation via television, SMS, letters, etc. is likely to work)
Do not see applicability to themselves (likely to be a small group of under- screened women = ~8%)	Provide advice on survivability (you can have <u>control</u> over this) Multiple, consistent reach-outs and reminders to encourage prioritisation (saturation via television, SMS, letters, etc. is likely to work) as well as testimonials to encourage identification of relevance to them
Fatalistic/what will be will be (likely to be a small group of under- screened women = ~4%)	Provide advice on survivability (you can have <u>control</u> over this, and early detection) Multiple, consistent reach-outs and reminders to encourage prioritisation (saturation via television, SMS, letters, etc. is likely to work)

 Table 8: Segmentation and potential responses

#### 4.5.8. Social media may be important in influencing women's understanding

Robinson et al. (2015) completed a focus group and survey study exploring women's attitudes towards social media for support about breast screening. It sought their ideas about what a dedicated breast screening hub or Digital Support Network (DSN) might comprise; how they would network with other women on the DSN; what format information might take; and whether a health professional should be available on the DSN. A socio-ecological framework was used to identify key influencers and potential barriers for the implementation of a mammography DSN. The study identified issues related to three intersecting concepts which influenced women's choice:

- 1. online conversations about health in general
- 2. online conversations about breast screening mammography and the culture of privacy which makes conversing about intimate health (either face to face or online) difficult, and
- 3. the three-yearly screening episode.

Together, this could mean an online breast screening network is challenging to sustain. Health professionals were also seen as essential for moderating potential misinformation shared by women although the participants were also insistent that 'truth' be shared.

Ghanouni et al (2016a) undertook a cross-sectional study to review a range of health websites in Australia (eight from New South Wales' cancer charities, breast screening providers, government agencies), and the United Kingdom to assess online information about overdiagnosis (in particular, DCIS). Information about overdiagnosis was included on six of Australian websites, with the authors noting that this could include information on:

- detection of breast cancer that would not become life-threatening or symptomatic
- DCIS (noting that DCIS is the type of cancer most likely to be associated with overdiagnosis), and
- that it is not possible to determine which cancers will become invasive/harmful.

Few websites (1/8) described that unnecessary treatment was associated with harm. Limited statistical information about overdiagnosis was provided on the Australian websites (compared to the NHS guidance). While this study is older, it might be useful to consider this when looking at the resources discussed in *part 5* of this report.

#### 5. Findings from the stocktake of resources

*Part 5* of this report describes the findings of the stocktake of resources to identify the range of <u>Australian-based</u> resources that Australian women might use to inform themselves about breast cancer risk and the benefits and risks of participating in population-based breast screening. There were two phases:

- 1. Desk-based review, and
- 2. Confirming resources from BreastScreen Australia programs.

This stocktake <u>only</u> looked at Australian websites. We acknowledge that many Australian women are likely to seek information about breast screening (including its benefits and risks) from a range of sources hosted in other jurisdictions. There may also be other resources developed and in use since the initial research was undertaken (2018).

A list of the websites covered in this stocktake and the methodology used is described in *section 2.4* of this report.

A list of all the resources and their URLs is included in *Annex A*. This includes listing these by the organisation (including BSA program) responsible for developing them.

We found three different risk assessment tools and some websites provided links to the tools, particularly Cancer Australia's risk assessment tool; however, risk assessment tools were outside of our scope and are not discussed further in this report.

# 5.1. Information about breast cancer and breast screening is widely available: we identified 227 resources, webpages, pamphlets and posters

There is a large amount of information about breast cancer and breast screening available across Commonwealth and state/territory health agencies, and Australian-based breast health and general health-focused non-government organisation webpages: we collected 227 resources from 36 government and non-government websites.

Resources are available in a variety of formats, including webpages, brochures, booklets, fact sheets, posters, and videos. Most of the resources contain a 'moderate' amount of detail (eg. an A4 brochure).

# 5.2. It is easy to find information about breast anatomy, breast cancer symptoms and types of cancer, and breast cancer risk factors

Similar information is available across websites, including information about breast cancer, the importance of early detection, the role of population-based breast screening, population risk and risk factors, and the harms and benefits of screening, although the depth varied.

Basic information about breast cancer and breast screening is easy to find through BreastScreen Australia; however, information was more difficult to find through some state/territory government health departments. This was expected in some ways given the mandate of BreastScreen Australia programs, whereas government health departments are not responsible for operating a screening program. This meant that some websites either provided only a link to the BreastScreen Australia website for their region or provided more comprehensive information on their website. Topic areas covered in the resources we identified were:

• Breast cancer in general including anatomical information about the breast, definitions of cancer, descriptions of types of breast cancer, breast cancer symptoms or information to support breast awareness, and diagnostic/treatment pathways (*n*=30).

Some websites provided links to other websites containing these resources or links to specific resources (eg, Cancer Council Australia's booklet: Understanding Breast Cancer) rather than containing information

- Population risk of breast cancer or an individual's risk of breast cancer, including modifiable and non-modifiable factors that contribute to overall risk (*n*=92), and
- Breast awareness and early detection of breast cancer (*n*=188) including benefits limitations of mammography as a screening test (*n*=27).

Please note that some resources covered multiple topics.

More information about available information on risk factors is provided in *section 4.3*. More information about the early detection of breast cancer is included in *section 4.4*.

#### 5.3. Some risk factors for breast cancer are well-articulated, others less so

While most of the information was concise, simple and did not specify the relative risk, a Cancer Australia webpage provided information to help people understand concepts such as absolute and relative risk, as well as the impact risk factors may or may not have on the development of breast cancer.

Resources identified a range of risk factors and usually described these briefly and categorized them by whether they are modifiable or not. The main risk factors identified were:

#### Non-modifiable risks for breast cancer

- Being female
- Increasing age (this was the most commonly described risk factor in all resources)
- Having a family history
- Being of Ashkenazi Jewish descent
- Having specific genetic defects (especially BRCA 1 or BRCA 2 defects)
- Having more dense breasts
- Having ever had breast cancer or having a certain breast condition such as lobular carcinoma in-situ
- Reproductive and hormonal factors including early menarche, late menopause and having your first baby after aged 30 years or never having a baby
- Ever using DES during pregnancy or being the daughter of a woman who used DES, and
- Exposure to radiation.

#### Modifiable risk factors

- Lifestyle factors such as reduced/low physical activity, smoking, being overweight or obese, drinking alcohol (more than two standard drinks per day), and
- Taking hormone replacement therapy/oral contraceptives.

Some resources explained that all women have a least one risk factor for breast cancer and that we do not understand the relationships between different risk factors well or how specific risk factors contribute to breast cancer (in general).

A lot of resources, particularly Cancer Council, focused on providing information on the management of modifiable risk factors.

#### 5.3.1. There is a lot of information about family risk but less about genetic risk

A lot of resources emphasized that familial risk is not the strongest risk factor for breast cancer (i.e., that often breast cancer is due to chance and can develop at any time or that 9/10 breast cancers occur in women without a family history).

We identified one resource from the NSW Centre for Genetics Education, which described in detail the risk posed by BRAC1 and BRCA 2 defects, including lots of simple graphics describing the risk at a population level.

Most resources discussed family history and genetic risk as separate risk factors but only some discussed the interrelationship between the factors and how this may impact on breast cancer.

Resources provide screening recommendations for women with a "significant" family history of breast cancer.

## **5.3.2.** There is some information available about breast density as a risk factor for breast cancer

Specific resources and information describing the risk posed by extremely dense breast tissue were more limited (n=17): most advice about breast density as a risk factor for breast cancer (or its impact on interpreting mammographic images) was provided on NGO websites including Be Dense Aware, Pink Hope, BCNA, INFORMD, three BreastScreen Australia program websites (NSW, Victoria and Western Australia) and some government agency sites but not all. Resources included webpage text, infographics and videos. Other organisations (including other BreastScreen Australia program websites) may also contain information about breast density but this was not presented in a way that was as easy to find or obvious or as a separate area of discussion (i.e., it may be included in text on a page about mammography more generally, rather than being highlighted alone).

Information provided on BreastScreen Western Australia's website is important to consider, given that this is currently the only program that provides women with a notification of their breast density. It provides factsheets for women regarding breast density (covering issues such as what breast density is and advice focused on the masking effect of density on mammogram). Information about breast density as an independent risk factor for breast cancer is not included in the consumer-focused pamphlets but it is included on the BreastScreen Western Australia website. BreastScreen Western Australia also provides a fact sheet on breast density for GPs/health practitioners. This focuses on describing breast density, noting the effect of increased density on decreased sensitivity with mammography and discusses the benefits and limitations associated with additional testing with tomosynthesis and ultrasound.

One resource (prepared by Pink Hope) reported on a survey<sup>3</sup> of women's awareness of breast density:

- 70 percent of women surveyed did not know or were unsure about whether breast density can increase the risk of breast cancer, and
- 70 percent of surveyed did not know or were unsure that breast density could obscure a breast cancer on a mammogram (with 80 percent of women surveyed being unaware of research about the masking effect of breast density).

While we have limited information on the methodology used by Pink Hope, given the findings from its survey, it is possible that more women may not be made aware of breast density as an issue unless they either specifically look for this information or go to a site where it is more prominent. This is predicated on the assumption that women engaging with Pink Hope may be more likely to be seeking information about breast cancer and risk than other women.

All the resources included a description of what breast density is (with many including images of mammograms of non-dense and very dense breasts to demonstrate the increased difficulty in seeing a cancer in very dense breasts). Topics that were generally covered include:

• descriptions of breast density (and what it is not) and its prevalence

<sup>&</sup>lt;sup>3</sup> From Pink Hope's 2018 Consumer Survey of approximately 1000 Australian women.

- how breast density affects the interpretation of mammograms (which was the most common way to discuss breast density's association with breast cancer rather than discussing the evidence that very dense tissue is an independent risk factor)
- the relationship between breast density and breast cancer risk, with one BreastScreen Australia program website describing density within the pantheon of other risk factors for breast cancer
- how breast density is measured, and
- whether women with dense breasts should participate in screening mammography (including discussion about additional tests).

Mixed information on how to manage increased density was provided across the websites. Several resources (including those from the National Breast Cancer Foundation, INFORMD, and BreastScreen Australia programs/government health agencies) noted that measuring breast density remains a challenge and that mammography remains the most effective way to detect breast cancer early. Another key point was that there is no definitive evidence suggesting that other tests are needed for women aged over 50 years and who have very dense breasts. Women were also given advice to be breast aware, to speak to their health professional if they have any specific concerns and that other tests (such as adjunctive MRI or ultrasound) come with potential limitations (including the risk of false positives and financial or emotional costs). Other sites (including Pink Hope) advised women to discuss developing an individually tailored approach to screening with the woman's health professional, noting that adjunctive ultrasound or breast MRI may be appropriate especially for younger women.

One resource (Pink Hope) provided an easy-to-read graphic that described:

- estimates of the number of Australian women who have dense breasts
- the relationship between increased density and breast cancer
- mammography's limitations for imaging women with very dense breasts
- women's awareness of breast density as a risk factor for cancer and its impact on mammography interpretation (discussed above), and
- breast density notification practices in the United States, with a call for notification to be available in Australia.

Some resources also noted the need for improved methods to quantify breast density. Further research into breast density (including evaluating the harms and benefits of notification, balancing women's right to access personal medical information and the need to develop evidence-based approaches to breast cancer risk assessment and early diagnosis) was noted by a number of organisations, including government agencies.

Some agency position statements (Pink Hope) supported the reporting and notification of breast density.

#### 5.4. Breast awareness and early detection were strongly promoted

All websites reviewed had a strong emphasis on early detection, including breast awareness and screening. A total of 188 resources include information about breast awareness and/or screening.

A lot of resources strongly emphasized breast awareness with information on symptoms and breast changes to be aware of and the importance of self-examination as an aspect of early

detection. Information provided by non-government organisations about screening was brief and generally included information about mammography as well other breast screening technologies that women may use (eg. ultrasound, MRI). Organisations provided this information generally advised women, particularly those at the highest risk of breast cancer, to discuss their suitably for mammography screening with their health professional (often the GP).

Given that BreastScreen Australia only uses mammograms in the screening program, information provided on BreastScreen Australia websites programs focused on mammography, with these websites emphasising that no other technologies have been proven as a screening test to reduce deaths from breast cancer. BreastScreen Australia program resources also emphasized that breast cancer can develop at any time (including between screening appointments): breast awareness was strongly encouraged.

# 5.5. Information about the limitations of screening with mammography and its potential harms is not as clearly articulated in general but is clearer in screening consent forms

The literature suggests that women may underestimate the harms of breast screening and have low awareness or understanding of overdiagnosis. While many resources emphasized the importance of early detection and screening, only 27 resources provided information on the potential harms or limitations of mammography screening. Some organisations provided information as a specific area of discussion or provided brief information on a page about mammography screening more generally.

The booklets and pamphlets with information about screening limitations are from BreastScreen Australia, Cancer Council WA, BreastScreen NSW, and BreastScreen Victoria. BreastScreen Australia's main resource ("BreastScreen and You") provides information to help women decide whether or not to take part on the BreastScreen Australia program and includes pictorial representation of the number of women affected by the potential harms (overdiagnosis, false positives and false negatives) at a population level (shown per 1000 women). Some state/territory websites also provide a link to this resource: we heard at interviews with BreastScreen stakeholders that this resource was well-used and liked (although no formal evaluations were available).

Websites that provided information about the limitations also included discussion on the benefits of screening, which could support the provision of balanced information to help women make an informed decision about whether screening is suitable for them and whether or not they should participate in the BreastScreen Australia program. It is not clear whether or how the information provided may help women to assess the information provided. Most organisations noted that women should be aware and take benefits and risks into consideration, but others advised women to discuss benefits and harms with their GP. Organisations in Western Australia were more likely to comment on the limitations in the context of an individual's decision and advise discussing the benefits and harms with their GP.

Despite the limitations of breast screening, most organisations providing information about limitations emphasise that regular breast screening is the best way to reduce mortality from breast cancer through earlier treatment.

Many resources did not use specific terms to describe limitations (such as overdiagnosis/overtreatment, the impact of false positives, radiation dose, etc.) and instead described what it means in practice for women participating in breast screening. Providing information in this way may make it easier for women to understand a technical concept; however, if women are specifically seeking information on "overdiagnosis", for example, and without knowing what it means this may make it difficult to search for the information. The potential harms and limitations of screening, and the key messages that are described in the resources included:

- Overdiagnosis
  - What overdiagnosis is, why it occurs, and the potential impact of delaying treatment or not treating detected breast cancer
  - The adverse psychological effects of potentially unnecessary treatments
  - That there is uncertainty around the extent of overdiagnosis and estimates vary widely; however, organisations support further research to distinguish between life-threatening and non-life-threatening cancers
  - Cancer Council WA provides a link to Cancer Research UK for further information<sup>4</sup>
- Radiation exposure
  - Most resources emphasise that mammograms are safe, and research shows the benefits of screening mammograms to find breast cancer early outweigh any potential risks from radiation exposure
  - BreastScreen Australia notes there is a small amount of exposure from radiation and compares the level of exposure from a screening episode to approximately 18 weeks of exposure to natural radiation in the environment; BreastScreen Victoria notes equivalence to 12 weeks exposure to natural radiation levels.
- False negatives (i.e. further tests done but breast cancer not found) and false positives (i.e. breast cancer is present but not found)
  - Organisations emphasized that mammograms are not 100 percent accurate and there is a chance that cancer will not be seen on a mammogram can develop during the time between screening mammograms (interval cancer). Some resources then went on to emphasise that women need to be breast aware and advise seeing a doctor if any symptoms occur.
- Not all detected breast cancers can be cured or treated (noted by three resources only)

Resources varied in the comprehensiveness of information and the number of limitations discussed. For example, some resources (myVMC, BreastScreen Northern Territory) only provide information on radiation exposure, whereas other resources typically provided information on overdiagnosis, radiation exposure, false negative and false positives. However, in general, many websites contained little information about overdiagnosis.

While most resources that provided information on limitations is in relation to mammography, one resource (Pink Hope) provided information about the limitations of MRI screening, particularly if women are not considered to have a high risk of breast cancer. The key messages focused on over screening and exposing women to unnecessary procedures (with psychological and financial implications).

<sup>&</sup>lt;sup>4</sup> The most comprehensive "resource" (noting that the intended audiences are organisations, health professional, medical colleges, and policy makers) is the Cancer Australia position statement on overdiagnosis

### 5.5.1. Information included in BreastScreen Australia consent forms and personal questionnaires

During or post-interviews, most BreastScreen Australia state/territory programs provided copies of the personal questionnaire and consent form used when women come in for screening. These forms often contained information about breast symptoms, breast cancer risk factors, and the benefits and limitations of breast screening. A summary of the information provided on the state/territory information sheet is provided in *Table 9a* (overleaf); information requested via the personal questionnaire and consent form is provided in *Table 9b* (page 92). There is a high degree of consistency in the information provided about the service but much more variance in information provided about the benefits and limitations and risk factors.

This information is usually only provided when women attend for screening, so non-attendees may not benefit from receiving the same information or having the opportunity to discuss the content with a trained and experienced health practitioner like a breast radiographer.

#### Table 9a: BreastScreen Australia information sheet data

BSA program	Includes information	about:				
	Benefits of screening	Harms of screening	Limitations	Breast cancer risks	Breast symptoms	Screening pathways
New South Wales	Forms not supplied					
Northern Territory	-	Missed cancer: mammography won't find all cancers; notes that the x- ray is safe and provides a low dose of radiation	Screening does not prevent breast cancer	-	-	Eligibility, breast awareness, preparing for the appointment, the exam + compression. Reading + recall
Queensland	Preventing death, less invasive treatment, reassurance	Overdiagnosis, over- investigation/false positives and missed cancers	-	Discusses family history (close relatives)	Notes BSQ is for well women: advises women to tell BSQ (noting that a screening mammogram may not be best test) or see their doctor first	Includes info about eligibility, the exam + compression, reading and getting results, recall if needed, what happens in two years; advises about breast awareness in between screens
South Australia	Check for early signs of breast cancer, easier to treat/better outcomes, reduces death (up to 41%), reassurance	Missed cancers + more aggressive treatment, interval cancers, overdiagnosis, false positives (further tests done but no cancer found), radiation	Doesn't report on benign breast conditions, effectiveness of mammography impacted by age and breast density		Notes BSSA is for well women: advises women to tell BSSA before making an appointment (noting that a screening mammogram may not be best test)	Includes info about eligibility, the exam + compression, reading and getting results, recall if needed, what happens in two years; advises about breast awareness in between screens
Tasmania	Best chance of detecting cancer early	Missed cancers, mammography cannot detect all cancers	-	-	-	Includes info abut eligibility, the exam + compression, reading + results, recall if needed, what happens in two years, breast awareness between screens
Victoria	Finding small breast cancers before they can be seen or felt and links to better outcomes	Radiation exposure and sensitivity. Recall is contextualized to false	Discusses breast implants and pain management during compression (and why this is needed)	Discusses family and personal history of breast and ovarian cancer	Advises women to see their doctor before the screening appointment	Includes info about eligibility, making appointments, during the

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BSA program	Includes information about:					
		positives and higher rates for prevalent screens				exam, results + recall, what to do in two years)
Western Australia	Forms not supplied					

Table 9b: BreastScreen Australia personal questionnaire and consent form

BSA program	Asks for informati	ion about:						
	Current use of HRT or oral contraceptives	Prior mammogram	Family history - breast	Family history - ovarian	Personal history - breast	Current breast symptoms	Other health issues	
New South Wales	Forms not supplied	Forms not supplied						
Northern Territory	-	$\checkmark$	-	-	-	-	✓ Implants	
Queensland	-	-	✓ Defined as first degree female relative under 50 years at diagnosis OR first-degree male	-	$\checkmark$	$\checkmark$	✓ Breast surgery including implants	
South Australia	✓ In last six months = HRT; taking OCP	$\checkmark$	✓ Defined as blood relatives in mother or father's family		$\checkmark$	$\checkmark$	✓ Leukaemia, lymphoma, chest device implant, pregnant, breastfeeding	
Tasmania	✓ In last six months	-	✓ Not defined	-	$\checkmark$	$\checkmark$	✓ Ovarian cancer, breast surgery, implants	
Victoria	✓ Current use, started after last mammogram	√	✓ Defined as first- and second-degree blood relatives	✓ Defined as first-degree female relative	✓ Also asks about treatment	$\checkmark$	✓ Pregnant, breastfeeding, breast surgery excluding implants	

BSA program	Asks for information about:
Western Australia	Forms not supplied

#### 5.6. Most resources did not address specific populations, but a few did

A total of 28 resources provided information for specific population groups of Australian women.

Some of the resources were in English but were culturally designed for Aboriginal and Torres Strait Islander women (*n*=4). Not all states/territory or non-government organisation websites have resources or sections specific for Aboriginal and Torres Strait Islander women. While many national and state/territory BreastScreen Australia resources were available, none specifically provided information to Aboriginal and Torres Strait Islander women on the limitations of screening.

A key BreastScreen Australia resource (eg. *Is BreastScreen for you?*) was available to download in 32 languages. Four state BreastScreen Australia programs also provided translated resources for some of their resources.

Four resources provided information about breast cancer and breast screening specifically for intellectually disabled women and their caregivers.

One BreastScreen Australia program provided information about screening for trans and gender diverse people.

#### 5.7. Short, simple messages are commonly used across resources

BreastScreen Australia program resources focused on a combination of providing information for women to decide if screening is suitable for them and encouraging women to participate in breast screening. These resources more commonly emphasized short, simple messages while other websites communicated more complex information. Common messages included:

- Early detection is your best protection, and
- Most women who get breast cancer do NOT have a family history of breast cancer.

# 5.8. Addressing fear directly to encourage adherence to screening is not a focus of communications

The findings from the literature review showed that fear and destiny-based/fatalistic beliefs can lead to avoidance of breast screening. None of the written resources directly address cultural beliefs about breast cancer; however, the resources provide information to help women prepare for their first mammogram. Examples include information about privacy during a mammogram and discomfort from compression of the breasts during a mammogram. Some of the websites also include videos from women who share their breast screening experience and personal stories, which may provide reassurance to women who have not had a mammogram before and to encourage them to be breast aware.

#### 6. Insights from Interviews with Breastscreen Australia State/Territory Program Stakeholders

*Part 6* of this report provides a thematic analysis of findings from semi-structured interviews with BreastScreen Australia state/territory program staff and stakeholders involved in providing breast screening services, undertaking breast cancer research, or providing breast

screening information to women and health practitioners. We have presented information thematically to preserve the privacy of interview participants (and the screening program they work for) and to capture both areas of agreement and difference across the following areas:

- Australian women's knowledge of and attitude or perceptions towards breast cancer risk and the benefits and risks of breast screening
- resources used to support women's understanding of breast cancer risk factors and the benefits and risks of participating in screening
- advice/insights into how best to effectively influence women's understanding of breast cancer risk factors and the benefits and risks of participating in screening
- communications needs and gaps in the information women receive and recommendations to address any issues raised, and
- any research or papers commissioned or completed on these topics *NB research papers have been integrated into Part 4 of this report where we are able to share the information*

The methodology used is described in *section 3.4* of this report. A list of interview participants is provided in *Annex C.* 

#### **Key findings**

Important contextual information influences our understanding of women's knowledge and beliefs about breast cancer, risk factors and screening. Much of this understanding is held in BreastScreen Australia state/territory programs, and we appreciate their engagement with us on this work. Key insights include that women are not a homogeneous group: there are many unique factors that underpin women's knowledge and their engagement with screening services. Often, research presents information about knowledge at a specific point in time for women who were involved in screening at that time (and who may no longer be): this has implications for the applicability of older research to contemporary settings, especially given the very significant changes in communications channels over the past 10 years. Another key contextual factor is that research needs to be clear about whether participants are regular screeners or are underscreened (including never-screeners) as women engaged in screening are likely to hold more positive views about screening than those who do not participate regularly. Encouraging a culture of co-design and engaging women to ask what they want to know and how are also fundamental to effective communications and ensuring informed decision-making. Interview participants told us that many things that reflect the findings of the literature review, as well as some new insights. Key findings included that:

- women have a good understanding of breast cancer, but knowledge about breast cancer as a group of diseases (rather than one homogenous disease) varies
- understanding of risk factors varies across and between cohorts of women, with some overstated and others underestimated, with knowledge underpinned by evidence gap
- women who have had some personal experience of breast cancer (either themselves or a friend/family member) are often better informed and Aboriginal and Torres Strait Islander people
   sex and increasing age are known risk factors but are often poorly understood, especially risk for women aged in their 40s and for women aged over 75 years, which creates confusion for women about when to start and stop screening

- family history of breast cancer is well-known as a risk factor but it is not wellunderstood and understanding of this risk often results in over-estimation (eg, the influence of first-degree blood relatives having breast cancer on risk compared to distant or non-blood relatives having breast cancer) breast density is not well-understood as a risk factor and its importance to screening participants seems to vary: in some jurisdictions, it is an emerging issue but it is not in others regardless of understanding and focus, a common position on breast density requires increased consensus on management and notification to reduce confusion and ensure confidence in the BreastScreen Australia program risk of breast cancer is a challenging concept to communicate well but there are ways that it can be communicated (eg, icon arrays, multi-level and layered information) women and health practitioners may not understand the difference between screening mammography and diagnostic mammography, or this may reflect service delivery choices/prioritisation the benefits of screening are well-understood but limitations may not be (and while
- The benefits of screening are wen-understood but initiations may not be (and while there is awareness of overdiagnosis/over-treatment, more information is needed) and care is needed to communicate balanced advice about benefits and harms with the risk of doing harm if a women does not screen and the need to achieve participation rates
- supporting informed decision-making requires continuous effort across multiple service touchpoints and managing implied consent requires considerable skill.

Interview participants also noted that each communications strategy works at least some of the time for some women but that a successful approach needs to involve multi-layered, multi-focal approaches across the whole of a woman's screening journey (i.e., providing for care, concern and dignity from her first screen to her last screen). It is also very important to pay attention to delivering content in a way that is culturally safe and competent and in a way that recognises different life stages may require different information. Information also needs to consider the needs of health practitioners as well.

Interview participants also identified a small number of research gaps and communications needs, including the need for research about breast cancer incidence in different populations and ways to manage overdiagnosis.

#### 6.1. Acknowledgments

*Allen + Clarke* would like to thank everyone who participated in interviews with our team. We appreciated your time, expertise and insights into Australian women's knowledge, attitudes and beliefs and your expertise in communicating with women about breast screening. We would also like to thank those organisational staff members who supported us with meeting arrangement assistance. Finally, we would like to thank the Australian Government Department of Health for its assistance in preparing for the stakeholder engagement, and for the opportunity to complete this important work.

# 6.2. Important contextual information impacts our understanding of women's knowledge and beliefs about cancer, risk factors and screening

BreastScreen Australia state/territory programs are expert at communicating with women to welcome them to the program, to ensure their comfort and satisfaction with services delivered, and to continue to engage effectively with women to ensure that they re-screen at regular intervals. They also hold a wealth of information about under-screened women, what drives women to not participate and how to engage with these women to encourage participation. Some of this knowledge is underpinned by good quality, targeted qualitative research; other knowledge exists anecdotally and is drawn from staff working directly with women in a screening setting. We acknowledge that some of the findings presented in *Part 6* draw heavily on anecdote, but we respect this as a form of evidence given the expertise of the interview participants.

Some insights provided by interview participants may be particularly pertinent to their screening population, their work/understanding of under-screened women in their areas, or to the way screening is delivered in that jurisdiction. These points of difference often offer as valuable an insight as areas of commonality; however, we have tried to present this information in a way that is mindful of the privacy of participants. No direct quotes are used.

Extrapolation of the interview findings requires care: women are not a homogenous group to whom one set of rules apply or who have consistency in knowledge and/or application of this knowledge to preventive health-seeking behaviours. We are mindful that some women are highly health-literate about breast cancer and screening whereas other women may not know much at all. There are also significant differences between women based on education, socio-economic, ethnic and cultural factors, gender identity, sexual orientation, and between those women who regularly choose to participate in breast screening and those who are under/never-screened. There are many potential unique combinations of factors that need to be considered. Understandings (or misunderstandings) about breast cancer and its risk factors is shaped by a woman's unique life experience. While some of the interview findings may have universality, we recognise that women are likely to be impacted and driven by different barriers, enablers, motivators and communications/engagement strategies (many of which were identified in the literature described in *Part 4*).

Other key points of note are that:

- women's knowledge is point in time only, and it can become outdated very quickly: for example, the way that women receive and digest information today differs greatly from how information was used 10 years ago: this reflects both changes in technology and changes within the screening cohort
- research can draw from 'the women who were' (i.e., research on women entering the BSA program might have drawn study participants who entered the program several years ago, depending on the time distance between the data collection and publication phases; this may influence the applicability of the research to women 'today' if there are significant differences between the 'women who were').
- women who participate in breast screening are choosing to be part of a program that (presumably) they believe in and endorse through their action to participate; there are likely to be significant differences in knowledge and potential selection bias between women who are regular screeners and those who are under-screened or never-

screeners: this needs to be considered in any research. *NB some of these differences are explored in some grey literature covered in Part 4 of this report* 

- cancer is a diverse and complex disease: increasing our range of responses and appropriate triaging based on tumour biology/diagnosed issue is needed to address concerns about overdiagnosis (rather than this being an issue of informed consent/women's knowledge), and
- we should establish a culture of co-design: ask women what information they want and how they want to receive it, being cognisant that differences in age, cultural/ethnic background, socio-economic status, gender and sexual orientation, and previous engagement with screening services are likely to impact on preferences.

#### 6.3. Awareness of breast cancer is high

Interview participants told us that women have a good general awareness of breast cancer, but this varies: some women are very well-versed, understanding that breast cancer is a complex suite of diseases; others know very little. Overall, however, there is limited understanding that breast cancer is a complex suite of diseases (not just one), the types of breast cancer, and how it develops.

Many interview participants commented that women have a sense of the incidence of breast cancer and are familiar with the statistic that "one in eight women will be diagnosed with breast cancer". Women who have some level of personal experience with breast cancer (either personally or through a social network) are likely to have a better understanding of breast cancer.

One concern raised by a few interview participants was that some women think they know more than they do and that they end up speaking authoritatively, but incorrectly, about breast screening. This can potentially perpetuate myths about breast cancer, risk factors and screening. An example cited was the promotion of the use of thyroid guards during screening mammography, by women who believed that an increase in low-grade thyroid cancer was linked to breast screening mammography (although the evidence does not suggest this is the situation).

# 6.4. Australian women's understanding and knowledge of breast cancer risk factors is variable and is likely to differ across population cohorts

We asked interview participants to explain their views on Australian women's understanding of breast cancer risk factors, including those that they think are well-understood, and those that are understood poorly or not at all. Interview participants generally provided unprompted responses about the following risk factors:

- Increasing age
- Family history and genetics, and
- Increased breast density (some interview participants only; others were prompted).

Other risk factors that were raised included modifiable risk factors (particularly alcohol consumption, long-term use of combined HRT and weight), gender, reproductive history and prior radiation exposure/exposure to radiation through mammography.

### 6.4.1. Different groups of women are likely to have different understandings about breast cancer risk factors

An overarching finding was that women have varying understandings of breast cancer risk factors. Some interview participants thought that some women had a good understanding; others thought that women's understanding was generally poor. Dimensions of this issue raised by interview participants included that:

- younger women or women who know someone who has had a breast cancer diagnosis or who have a family history of breast cancer or are part of the "worried well cohort" are more likely to have a greater level of understanding about breast cancer risk factors: these women tend to be more proactive in seeking information about breast cancer risk factors
- Aboriginal and Torres Strait Islander and CALD women, or women who live in low socioeconomic areas or remote areas generally have lower levels of understanding of breast cancer and its risk factors. Some jurisdictions have received feedback that CALD women want more information about everything, including risk factors, and
- some women just do not want to know about their risk factors and how to reduce the risk of breast cancer (and this is ok).

Interview participants considered that some risk factors are not well understood at a population level. Some interview participants thought that some risks are significantly overstated whereas others are understated. Importantly, one interview participant noted that the evidence is not settled for some risk factors, and the lack of consensus can drive misunderstandings for women themselves ("if we don't know, how can we expect women to know?"). One interview participant noted that while there is a basic level of knowledge about breast cancer, information is at times contradictory and consequently, actual knowledge of risk is diluted. As a result, some women may over or underestimate the factors that contribute to their individual risk of breast cancer. Participants suggested that the relationship between a woman's knowledge of breast cancer risk factors and personal susceptibility needs to be strengthened as some women may understand individual risk factors but have difficulty quantifying or applying that risk to themselves. These variances are explored in the following sections.

### **6.4.2.** Sex and increasing age as risk factors for breast cancer are poorly understood and more conversations are needed

Interview participants from all jurisdictions considered that, at a population level, the two strongest risk factors (i.e., increasing age and being a woman) for breast cancer are not well understood. Misunderstandings included the association of age and the risk of breast cancer with some women thinking the risk is higher than what it is for younger women. This is often seen in queries by younger women (aged under 40 years) who would like to access the screening program and women in the eligible age cohort (aged 40 – 49 years) deciding to screen. Interview participants spoke about receiving queries from younger women through social media, call centres and during community outreach events. When asked, women often identified the average age for a breast cancer diagnosis as being aged 40 to 50 years.

Celebrities who have had a diagnosis for an aggressive breast cancer at a younger than average age often receive a large amount of media attention. Interview participants considered that this may influence how age is perceived as a risk factor. While this media attention may raise general awareness of breast cancer and breast cancer risk factors, a spike in screening engagement may

not correlate to an increased understanding, as anxiety is the factor that drives people to screen during these spikes.

Women who are aged 75 years and over are eligible to participate in screening but are not actively invited for a screening. The reasons for taking this approach are not generally well-understood. Partially, this is due to the difficulty of providing sensitive, balanced information about the increasing risk of developing breast cancer with increasing age and program cost-effectiveness (when screening is designed to reduce mortality from breast cancer, not breast cancer incidence). Interview participants from one jurisdiction discussed how they provide more information to women aged 75 years and over, articulating that they may not be suitable for screening and explaining the reasons why (i.e., likely co-morbidities and life expectancy). Interview participants noted that women often find this very confronting as breast screening is something that is personal to them. Most interview participants across various jurisdictions encourage women aged 75 years and over to discuss with their GP if they should continue to screen (with messages focusing on either that they should not if they have other significant comorbidities including dementia-related illnesses or continuing screening provided they remain otherwise healthy).

# 6.4.3. Women are generally more aware of personal risk factors, especially family history, but most do not correctly understand what the family history risk entails

Most interview participants considered that many women overestimate the risk of breast cancer due to risk factors such family history and genetics. Interview participants across all jurisdictions commented on women having a greater awareness of family history as a risk factor, relative to other breast cancer risk factors. Some interview participants considered that women with a family history of breast cancer may be more informed about breast cancer and its risk factors. These interview participants also thought that these women perceive themselves to have a higher relative risk of breast cancer. This is closely connected with the perception that younger women are at a higher risk of breast cancer.

While women may have a higher awareness of family history being a risk factor for breast cancer, many participants thought that this risk factor, and the definition of family history, is not well understood by women. There was a misconception that women must have a family history to be at risk of breast cancer, and women are often surprised to hear that 90 percent of breast cancers occur in women who do not have a family history. Interview participants noted strong myths that women without a family history of breast cancer are not at-risk. Some programs have responded to this (i.e., NSW's *Not in my Family* campaign).

There is also not a good understanding that family history means having one or more blood relatives who have had breast cancer, and how this risk differs between the degree of relativity. For example, participants used the example of women being concerned about their personal risk due to an in-law (i.e. non-blood relative) or a distant relative having a breast cancer diagnosis. The importance of age at a family member's diagnosis was also not well-understood. Interview participants also said that the difference between family history risk and genetic risk (i.e. carrying a BRCA mutation) is not well understood.

Interview participants considered that women may overestimate their family history risk because it is included in most state/territories' personal questionnaires (discussed in *section 5.5*), and discussed during the screening consultation, whereas other risk or protective factors are not discussed. They said that this could increase women's awareness of family history, but it may also skew their perception of the magnitude of the risk, especially when compared to other risk factors.

## 6.4.4. Breast density is not well understood and is the elephant in the room for some (but not all) BreastScreen Australia state/territory programs

Responses to questions about women's awareness/understanding of breast density (either as an independent risk factor or its potential masking effect) varied. For some interview participants, breast density was considered to be a more minor issue, either due to state/territory program parameters or because women themselves are not asking a lot of questions about breast density at this time. One interview participant considered that it is important to contextualise breast density: it is one risk factor of many.

For many other interview participants, breast density is a significant issue. These interview participants noted that BreastScreen Australia state/territory programs are increasingly receiving queries (through social media, emails, and during screening) about breast density. Some interview participants said that women perceive breast density to be a greater risk than what it is and often attribute density as the cause of a diagnosis. One interview participant said that the perception of breast density as a risk factor has been exaggerated, in part due to the information provided by lobbyist groups and discussions in online forums. Another participant (from a different jurisdiction) considered that breast density is currently under the spotlight in the same way that HRT was a decade ago.

Based on the queries received, there appears to be a lot of confusion about what density is and its impact: women are focused on knowing whether they have dense breasts rather than what this could mean for them in terms of risk, masking cancers on mammogram and management strategies. Specific comments about the misconceptions of breast density that interview participants discussed, included that breast density:

- relates to the size or firmness of the breast, and
- appear as being black on the mammogram (i.e., density is radio-opaque).

Interview participants also reported differing levels of queries from GPs directed towards the program. In general, interview participants considered that clinicians' understanding (including GPs and staff within the BSA program) of breast density varied, which may be due to a lack of established consensus about if/how to tell women about their individual density and what advice should be provided to manage risk. Participants said that it is difficult for women to understand the risk associated with breast density if clinicians do not have the evidence needed to provide a clear understanding of the risk posed (and to whom) and if they cannot provide advice to women on management. Without a clear management pathway for breast density within the program, it creates confusion and may impact on women's confidence in the screening program. Some interview participants also advised that they feel somewhat 'stuck' with regards to how best to go forward on whether to notify density or not, requesting further advice from experts on consistent messages for women.

There is variance in the way that breast density is discussed, managed, and reported within the BreastScreen Australia program, with notification only routinely occurring in Western Australia. Most interview participants said that they do not proactively discuss breast density at a screening appointment or in clinics; however, they may provide general information about breast density (not specific to the individual's density) when asked. Two jurisdictions further discussed their experience of providing breast density notifications to women. The jurisdiction that previously reported density (Northern Territory) noted that it has not received adverse feedback from women for no longer reporting density; however, interview participants noted some anecdotal evidence that suggested some women have moved to screening privately. This may relate to perceived availability of density advice, but this is not certain. Western Australia

currently reports breast density. Its communications focus on the masking aspect of breast density, as opposed to breast density as a risk factor. Interview participants noted that this assumes a duty of care to inform women and GPs about the decreasing sensitivity of mammography with an increase in breast density.

# **6.4.5.** HRT use is a known risk factor, but some interview participants thought there are relatively infrequent queries about it now

Along with family history, HRT use is included on most of BreastScreen Australia state/territory programs' personal questionnaires (discussed in *section 5.5*). When prompted, some interview participants considered that provision of questions about HRT use may skew women's perception of HRT as a risk factor for breast cancer (in addition to there being a lot of misinformation about the relationship between HRT use and breast cancer available in the public domain). Some interview participants also noted that HRT is known to increase breast cancer risk, but it does not seem to be as high on women's radar as it was 10 years ago, noting women's concerns may have shifted to increased breast density. Interview participants also said that if a woman is concerned about their risk of breast cancer due to HRT, then they are referred to their GP. This relies on the GPs knowledge and understanding of HRT as a risk factor and how they convey this to the woman.

#### 6.4.6. Modifiable risk factors are often not known or underestimated

Most interview participants did not mention modifiable risk factors without prompting from the interviewers. When responding to questions about women's understanding of modifiable risk factors, most interview participants mentioned the association between alcohol consumption and the risk of breast cancer, noting that it is not well understood. The reasons behind this are unclear; however, interview participants suggested that the messages about alcohol intake can be confusing (for example, advising no alcohol or moderate consumption of alcohol).

In addition, interview participants noted that breast cancer is not perceived as being strongly associated with lifestyle factors like other types of cancers are (eg. lung cancer and smoking), and awareness about prevention is generally low. Other lifestyle risk factors such as diet, exercise and weight are also thought to be underestimated. Program interview participants said that they generally do not receive questions about these risk (or protective) factors from women and some considered that women do not appreciate that there are things that they can do to reduce their risk of developing breast cancer: breast cancer can be seen as something that just happens.

Interview participants considered that it is difficult to gauge women's awareness and understanding of protective factors for breast cancer as they are not specifically discussed during their interactions when women are screened. However, of the protective factors for breast cancer, participants considered that breastfeeding is a better-known protective factor.

# **6.4.7.** Myths abound: there are misconceptions about factors that are not associated with a risk of breast cancer

Some interview participants also discussed misconceptions about risk factors that some women hold, including using antiperspirant, wearing a bra, stress, injury to the breast, and having a mammogram. Increased risk of coronary heart disease from screening was also described as an example where women may have misunderstood online information relating to other cancer therapies. Interview participants emphasized that evidence-based, consistent messaging about risk factors must be available as the first source of information for women (although we recognise that finding trusted information online can be challenging).

Social media and peer-to-peer forums can be a source of information about breast cancer for women; however, interview participants told us that women often perceive themselves to be better informed than they are, especially if the platform is social media. Some women speak with authority about "facts" that may be based on what they have heard through friends or internet articles. This can create a perpetuation of myths in online forums.

## 6.4.8. Risk is a difficult concept to understand, but it can be communicated in different ways to increase comprehension

Participants at all interviews acknowledged that communicating risk (in either absolute or relative terms) is hard. Risk (at a population and individual level) is a complex statistical concept and it is difficult to understand and communicate to people (irrespective of gender, type of disease and underpinning health literacy). Presenting risk in an evidence-based, yet appealing and understandable format for a range of audiences is a challenge. From focus group testing of campaign materials, some interview participants told us that there is no 'right' way to present risk information. Other considerations included:

- individual preferences between visual and written (word, icon or numbers) depictions of risk
- classifying risk by type (lifestyle, medical, genetic, reproductive, etc.)
- a preference for absolute risk over relative risk; however, this information is not available across multiple risk factors meaning that it cannot really be completed accurately, and/or
- providing information about risk factors in a variety of formats with a "breadcrumb" approach to the level of detail (eg, consumer-focused then technical detail then access to a full evidence review).

Some interview participants thought that communications to women should solely focus on population-based screening risk; however, others thought the BreastScreen Australia program should be preparing to provide information about women's personal risk.

# 6.5. Understanding of the parameters of the BreastScreen Australia program varies

BreastScreen Australia state/territory programs are well-known with high brand recognition, and there is a large amount of information about the programs provided online, through resources and other direct service user communications. Interview participants considered that there are some important dimensions of a population-based screening that are generally not well-understood by women: issues raised included potential misunderstandings that screening is for well women and that it needs to be completed at regular intervals, and confusion about the program being free for women aged older than 40 years but only invited from aged 50 years.

### 6.5.1. Screening is for well women: BreastScreen is not a diagnostic service for women with breast symptoms

Women commonly do not understand that breast cancer can develop without symptoms. There is a lack of awareness that asymptomatic cancers are most often detected through screening. Some interview participants thought it important that there is a change to the narrative about

breast cancer detection to also include the way that we detect breast cancer is through screening and finding very small cancers; not just by feeling for lumps or other breast changes.

Interview participants said that there is a lack of understanding of the difference between screening and diagnostic mammography (both among women and among health practitioners, opinions about whom are discussed in *section 4.2*). Screening programs in all jurisdictions ask women about breast symptoms on the personal questionnaire (see *section 5.5*), and interview participants from every jurisdiction said symptomatic women present in screening clinics. They noted that women often do not understand why they should not book a screening appointment if they have breast symptoms. This confusion may also be underpinned by different approaches to screening women with breast symptoms taken by state/territory screening programs: some programs provide a screen for symptomatic women; others refer the women to their GP (to receive a referral for a diagnostic mammogram). Drivers for completing a screening mammogram on a woman with breast symptoms include that it may be cheaper and faster for her than accessing a diagnostic mammogram (which may be a factor when symptomatic women present at screening).

#### 6.5.2. Screening should be regular: it is not a one-off procedure

Interview participants also said that many women, particularly in remote areas, have no concept of screening as a procedure that needs to be done regularly to detect cancer early. This may be why some women present with advanced cancer as they have the perception that they are "safe" after they have had one mammogram.

## 6.5.3. There is confusion about the age at which to start and stop screening, and why these age bands have been set

In addition to the BreastScreen Australia program being appropriate for women without breast symptoms only, interview participants discussed the difficulty of articulating the program's parameters to women who are not invited or are not eligible for screening. This is closely related to the low understanding of population risk compared to individual risk. Areas of confusion that participants indicated include:

- why women aged 50 to 74 years are actively invited to participate when other eligible women (those aged 40 to 49 years and 75 years or over) are not invited
- the age women should start screening, and
- why the screening interval is two-yearly for most women in the program (and yearly for women at a high risk of breast cancer).

That this is hard to communicate was acknowledged.

#### 6.6. Understanding benefits and limitations of breast screening varies

We asked interview participants to tell us about their views on Australian women's understanding about the benefits and limitations of participating in breast screening, particularly whether there are benefits that are well-understood (or not) as well as harms. Much of the information provided in response to these questions was anecdotal; however, research exploring women's understanding (where provided) is discussed in *section 6.10.* We also asked about how to effectively influence or improve women's understanding of breast screening (the results of this question are discussed in *section 6.4*).

Some interview participants noted that insights into women's awareness and knowledge about the benefits and limitations of the screening program are often seen through the lens of women who have already made the decision to attend screening. In some jurisdictions, this may only be half of the eligible population that have chosen to attend screening. The exact reasons and therefore the understanding of benefits and limitations within women who do not attend screening may not be clear.

## **6.6.1.** The benefits or screening and early detection are generally known, but the purpose and limitations of screening may not be well understood

We heard that BreastScreen Australia is a trusted brand, is seen as a safe place to go and that it has a very strong reputation. Some interview participants noted that any negative information included on social media pages is often moderated by women themselves in favour of more positive messages. This is one of the drivers of women's over-estimation of the benefits of screening.

Interview participants told us that the benefits of screening are better understood by those who choose to have regular screening mammograms; however, the benefits can be over-stated by women when they receive an "all clear" message. This could be related to how women understand the development of cancers and how screening by mammography works, as interview participants also described women having a lack of understanding that one of the potential outcomes of a screening exam is the possibility of being recalled for further testing and a cancer diagnosis. Some interview participants thought that there was a tick-box approach to screening. This most commonly presented in relation to statements like 'women come in just before their holidays so that they can get it out of the way: they are not thinking about a possible diagnosis'.

Interview participants considered that there is generally a low understanding of the limitations of screening. While information about the limitations is widely available across the BreastScreen Australia program, it is unclear whether women use this information deeply and consider the application of these issues to the own situation. One interview participant raised that this could be due to the way the BreastScreen Australia program has been promoted since its inception and an information bias towards increasing participation.

#### 6.6.2. The sensitivity and specificity of mammography is not well understood

Most interview participants considered that mammography's sensitivity and specificity are not understood by the majority of women who attend screening: there is a spectrum of certainty depending on the age of mammography units and women's personal factors and the consequence of this can be equivocal results. Another related issue is women's understanding of the role of age and that mammography is a less sensitive test in younger women (including those aged 40 to 49 years). Limited understanding of sensitivity often underpins women's confusion about why women in this age group are not actively invited to screening.

Interview participants emphasized that women need to understand that a cancer can be missed during a screening mammogram, but this must be balanced with the message that it is still important to attend screening at the required screening interval. Information about the sensitivity of mammograms is provided on consent forms; however, many women do not read or understand this information.

Interview participants also considered that interval cancers were not well understood. There is a misconception for many women that once they have received an all clear from a mammogram, they do not need to receive another mammogram or they are protected from developing breast cancer. This also links to the lack of understanding of breast cancer as a disease, and that aggressive cancers can develop rapidly (hence a need for screening + breast awareness).

#### 6.6.3. There is awareness of overdiagnosis/overtreatment, but this not well understood

Interview participants told us that there is a general awareness of the concept of overdiagnosis/overtreatment but there are mixed levels of understanding (from being very educated to having no idea). Similar to breast density, there is limited clinical consensus on how to identify and manage overdiagnosis/overtreatment when it is unknown if a lesion is cancerous, pre-cancerous or benign. This makes it difficult to communicate the issues and provide advice to women. Anecdotally, many interview participants said that women who are faced with a breast cancer diagnosis do not feel like they undergoing an unnecessary procedure to have it treated: they are grateful for the further investigation and would rather have the lesion removed (if this is required) than monitor it. Women also consider it important to have a full suite of tests on a lesion that may require further investigation. Some participants told us that women who are recalled for assessment or undergo treatment are strong advocates for screening and are enthusiastic about rescreening. Please note, this differs from the AIHW's 2018 report where false positives are less likely to rescreen in some jurisdictions.

Some interview participants also raised concerns about the media coverage on overdiagnosis/overtreatment and of not considering the opinions of women who are eligible for screening. Interview participants reported that women have said that they would rather have overdiagnosis than missed diagnosis. These interview participants were concerned that overdiagnosis/overtreatment is driven by academics and also within breast screening programs in overseas jurisdictions where the performance standards are not as strictly regulated as BreastScreen Australia. Underpinning this concern was anxiety about any adverse impact on screening participation that could result in harm to an individual woman for not screening and perceptions that BreastScreen Australia is 'constantly having to justify its existence when it does save women's lives'.

Some jurisdictions provided information about overdiagnosis/overtreatment during the screening process. One noted that it would like to be able to provide more evidence-based information to women about overtreatment at the outset and the different treatment options available to them – and that this is a gap in the whole program.

#### 6.6.4. Radiation exposure is a concern for some women

Interview participants told us that some women (generally more educated or informed women) appear to be very concerned about radiation exposure when they present for screening and for other women, it is not a concern. While some women may ask about radiation exposure during a screening exam, it is generally not a major concern as they have already made the decision to attend screening; however, there are some women who do not attend screening at all as they are concerned about their risk of developing cancer due to radiation exposure. Interview participants also indicated varying levels of queries across the jurisdictions. One jurisdiction noted that they receive more queries about radiation during assessment clinics due to additional dosage and whether the radiation can cause breast cancer. Interview participants considered that some women overmagnify the risk associated with radiation exposure from mammography and do not understand the relativity to other radiation exposures (e.g. CT scan, airplanes, natural sunlight) or that there are strict radiation exposure standards that the program adheres to.

# 6.7. Informed consent: do women actually want to know if they have breast cancer?

Several areas of conversation during interviews focused on informed decision-making specifically. Interview participants from several jurisdictions noted that women are often surprised to be recalled for diagnostic procedures. This can be seen when women book a screening appointment before going away for an extended period. This has implications for ensuring that women do fully consent to screening in that they understand the purpose of this exam.

#### 6.7.1. Providing balanced advice about the benefits and harms can create tension

One of the key tensions between interviews related to the balance of information about the benefits and harms associated with screening and the potential impact of information about limitations on overall participation. Some women are supportive and strong advocates for screening; some interview participants thought that these women would attend for screening regardless of whether further information on harms was provided; other women are more likely to be influenced by the provision of information. Overall, there is a need to balance:

- Clear evidence that breast screening detects cancers early and saves women's lives
- Evidence-based information about the potential harms and limitations of mammography (as well as the benefits)
- The risk of providing advice that harms a woman if she chooses not to screen because of concerns about harms, and has a cancer detected at a later, more advanced stage, and
- Meeting BreastScreen Australia participation rates (noting that the cost-effectiveness of breast screening depends on achieving a sufficiently high participation rate, calculated at 70 percent for Australia's programs).

Striking this balance, and ensuring informed consent, can be tricky territory to navigate.

#### 6.7.2. Supporting informed decision-making is a continuous process

Interview participants told us that informed decision is a continual process: it is important that it happens at the prevalent screen and all incident screens. There needs to be continuous engagement throughout a woman's screening journey. It is important not to assume that because a woman has screened once that she will remember the information and not have further questions at later screening appointments.

Informed consent is built into the screening process across all jurisdictions in varying ways, including in personal questionnaires (see *section 5.5*) and in a written consent form. In written information, the range and depth of information about the balance of benefits and harms varied. Further, some interview participants told us that some women do not read the information provided in the consent form and that there is some concern about how much information women take in when attending for screening. Other women are more proactive at obtaining information to make an informed decision and there was confidence that they have a good understanding of the balance between benefits and harms.

#### 6.7.3. Managing implied consent requires skill

Interview participants noted that there is no right or wrong way for a radiographer to provide information, but advice delivered with care, concern and dignity is likely to resonate well with women in terms of their overall experience and their sense of safety. Another important

component is overt/implied consent during the actual mammogram: good clinical practice involves the radiographer remaining alert for any verbal or physical/behavioural expression which may indicate a change in consent (especially for women whom consent is implied rather than given). Related to this, some interview participants discussed the issue of informed consent for women with severe intellectual disabilities, severe co-morbidities or other issues where consent is difficult to obtain (such as a woman with dementia). This can be an area where it is very difficult to for some individuals to provide informed (or implied) consent. In such cases (where consent must be implied due to dementia, for example or where another serious comorbidity such as a terminal illness means that detecting breast cancer is not going to change the fact that a person is dying), the harms can be greater than the benefits if there is a screening result requiring further investigation. Some interview participants noted that it may be acceptable to consider not screening these women. A high degree of skill is needed to navigate these conversations safely.

#### 6.8. Screening intention and choice: passive decision-makers?

Although some jurisdictions have done market research to target screening campaigns, interview participants noted that it is hard to understand what motivates women to make an appointment and attend screening, or the reasons why other women do not attend screening. Some interview participants considered that for the majority of women, attending screening is a passive decision when they are prompted to screen through a reminder or when the mobile screening bus is in their area.

Interview participants described similar barriers to the published and grey literature that influence a women's decision to participate (and continue to participate) in breast screening, including:

- fear of pain of the procedure (or because a family member/friend reported the screen to be painful)
- body image concerns during the procedure
- a sense of low self-worth and therefore not prioritizing attendance
- fear of diagnosis, fatalistic beliefs, and not wanting to know if they have cancer
- choosing something else (eg, self-examination, which some women consider to be an evidence-based substitute to mammography), and
- cultural factors, particularly in rural and remote areas where access to screening services may depend on when they have access to the mobile screening unit: women can easily miss their regular screen if the screening bus is only available for a short period of time and other things are happening (eg, they are away, men's/women's business, etc.).

Interview participants noted that one of the most important factors for repeat screening is the interaction between a woman and the radiographer during screening. This includes providing compassionate care during the screen as well as emphasising when the woman should have her next breast screen.

Interview participants also discussed competing priorities in women's lives as a barrier to attending screening. For many women, screening is not a priority when they have more significant health issues, or they are juggling complex lives. Interview participants emphasized that accessibility is a major influence on screening attendance. Enablers for some women may
include providing opportunities to screen after hours, a mobile screening service closer to their home or workplace or picking women up from their house to take them to screening.

## 6.9. Communications

We asked interview participants for their insights about what is important when communicating complex clinical information about breast cancer risk to women. There was a high degree of consistency in responses received and which we consider are well-embedded in the communications practices and processes used in different BreastScreen Australia state/territory programs.

One overarching comment that bears repeating is that women do not only seek information about breast symptoms, breast cancer and risk factors, and screening from BreastScreen Australia. The following comments need to be considered in this context.

# 6.9.1. Each communications strategy works for some women: multi-layered, multi-focal approaches across a long time-span work best

One clear theme across all interviews was that different women respond to different communications/engagement strategies in different ways – from finding an approach engaging to having it not resonate at all or to be confusing. Mindfulness is needed to ensure that information is provided through multiple points of engagement with women and through various modalities. This is critical to messages landing well with a wide range of women. There may also be differences in the way that programs communicate with women who screen regularly and those who are under-screened.

Related to this was a finding that all communication strategies used by BreastScreen Australia state/territory programs will have an impact for some women; however, some women may need to hear the messages many times before they become ingrained. Interview participants offered a wealth of information about different approaches that they had found to be effective (or not). Key principles included:

- Ensuring simple, short evidence-based information is easily available, in the places where women are looking and provide that information multiple times, in different ways
- Asking women about the information they want and how they would like to receive it: never make assumptions
- Recognising that different motivators<sup>5</sup> will resonate with different women (even within one cohort such as a cultural group or age-band)
- Communicating with care, dignity and concern at all points of the screening engagement:
  - This includes invitation, pre-screening exam, during the exam, and post-exam), but especially during the screening appointment can be an effective way of transmitting information but it is time-limited (and some women need more time to receive and understand information)

<sup>&</sup>lt;sup>5</sup> Segmentation based on whether women are regular, lapsed/under-screened or never screeners is an issue clearly identified in the literature, and in grey material presented by some BreastScreen Australia state/territory programs. Results from this are discussed in *Part 4* of this report.

- Communicating with screeners between appointments to discuss advances in breast imaging or other program changes
- Using multiple touchpoints with a strong digital presence (online information, testimonials, letters, texts, emails, social media, opportunistic reach-outs, etc.) across a long timespan (although interview participants were keen to ensure that women were not put-off from the program by spamming)
- Using simple, plain English language (in resources and clinical interactions) that is evidence-based: information should also be transparent to support informed decision making but not delivered in a patronising way
- Creating messages that are built around hope, rather than fear (eg., do it for your family, by screening I am hoping that if I have cancer it will be detected early and I will survive) and which take a well-woman's approach to managing health
- Providing for a low health literacy without making assumptions about what women do or do not know
- Being aware of the state/territory legislative context in which screening programs operate as this can restrict what information can be shared, with whom and when
- Considering sharing information with local politicians about screening rates in their areas (a different kind of local champion), and
- Starting communications early and continuing through a woman's screening life-long journey: all information, particularly the limitations of screening, should be provided at the outset when women provide informed consent for a mammogram but that this should be repeated at all subsequent engagements as well.

Another key point raised by interview participants was the need to provide information in layers, from the very simple through to more complex, scientific data about the balance of benefits and harms associated with screening. Interview participants emphasized that across all population groups, some women may want information about the evidence to make an informed decision and others only require the information needed to book and attend a screen. There should be a layered approach to providing information from to cater for health literacy level and information needs and preferences. This could include using multi-modal formats such as digital/interactive, social media, and hardcopy resources.

Peer-to-peer education was also seen as important provided that women acting as peers were well-informed about breast cancer, screening and myths themselves. Some interview participants seemed to indicate that well-informed peer-to-peer communications is fairly easy to achieve, citing evidence of the "self-moderated" nature of some BreastScreen social media sites. Other interview participants thought that online testimonials with women talking about breast cancer and its risk factors could encourage women to screen regularly. They considered that it is important to talk about regular screening as an aspect of a healthy lifestyle and reward women with taking proactive approach to their wellness.

In some jurisdictions, interview participants told us that breast screening media campaigns result in a spike in screening appointments, and in other jurisdictions the participants considered that print and TV media does not seem to influence engagement in screening (aside from short spikes following the diagnosis of a celebrity or prominent community member).

#### 6.9.2. Pay attention to culture when communicating to women

An interesting insight focused on the need to pay particular attention to cultural context when communicating with Aboriginal and Torres Strait Islander and CALD women. Some interview participants were keen to ensure that resources are not just translated from English, but that they were put in a cultural context that resonated with the intended audience. They told us there is sometimes a reliance on translated materials in the BreastScreen Australia program to meet the needs of CALD women. In the past, some translations have not been accurate and/or they have not included important cultural context or given thought to the health literacy of readers which would help the reader make sense of the content. Such "misfires" may not recognise women's information needs (including their ability to navigate a complex and foreign system) and the information provided may not actually be useful in terms of information provision about screening and decision-making. The assumption is that women are given written information and will use this to make an informed decision (regardless of whether the information is accessible or resonates). Related to this was a suggestion that programs may be spending a lot of money on translating substantively similar resources. There was a query as to whether there could be a single set of CALD resources used by all programs. This might also help with some of the costs associated with translating resources into languages where there is uncertainty about how many women will engage with it (and this was a related point: how do we know how many women might want a resource in a particular language).

Examples of improved cultural competence in communications included:

- Recognising cultural context such as women's priority for personal health issues
- Providing a range of ways to reach-out to and engage women in their communities (eg, invitation phone calls in their first language, group bookings, culturally competent clinical settings, culturally safe staff, community events, peer-peer contact, close engagement with respected Aboriginal health workers, etc.)
- Using local champions and ambassadors to spread messages about breast cancer and early detection: some interview participants spoke positively about community education sessions to overcome the barriers of language and health literacy which, although resource-intensive, was considered to be more effective than providing translated hard-copy resources
- Recognising that cultural beliefs are an important factor for Indigenous people's participation in screening, sometimes more so than their knowledge or understanding of risk factors: Aboriginal and Torres Strait Islander health services and nurses are pivotal in this space they are in the community to provide information in a meaningful way and encourage women to look after themselves through screening
- For Aboriginal women living in remote areas: including images need to reflect their reality (eg, yarning circles in a bush setting, not an urban setting)
- Ensuring that any translated materials are accurate: it is easy to mis-translated complex clinical information, and
- Recognising that yarning is not restricted to Aboriginal and Torres Strait Islander women and that talking through ideas with peers/friends is a common way that women share information and experiences.

#### 6.9.3. Women need different information at different life-stages

Some interview participants noted that the information provided tends to be standardized in content and delivery across all potential age ranges/life-stages. Most information is focused on women who are actively invited to participate in breast screening (i.e., women aged 50 to 74 years). They thought it important that information provided meet the needs of various age groups, including women aged 40-49 years. Some interview participants also considered that it could be worthwhile to provide information about breast care specifically for women under 40 years, which may also help to engage them in breast screening later in life. Other interview participants highlighted the importance of providing clear and honest information to women over 75 years or over about the decreasing benefit of screening for this age group depending on life-expectancy.

#### 6.9.4. Communicate more about risk factors but recognise that communicating about risk factors is complicated by the incompleteness of our knowledge

Communicating about risk factors was one area where a number of interview participants thought that more advice and information could be provided to women. Some key points included that communications should focus at a population-level, rather than personal risk. Women can become aware about risk factors through general population information, but they should be directly linked to breast cancer where possible too. Other interview participants thought that clear, consistent messages about risk factors and a greater focus on preventive messages to reduce risk from lifestyle factors would be helpful; however, some also cautioned that information about risk factors (particularly lifestyle risk factors), does not create a sense of blame for women who have had a breast cancer diagnosis. Underpinning these sentiments was the view that it is sometimes just difficult to communicate when we do not have a strong understanding of individual risks, or how a suite of risks may interact.

#### What does not resonate well with women? 6.9.5.

We asked interview participants to identify any particular methods or messages that they thought did not resonate well. There was some variability both within interviews and between different interviews. Some interview participants thought that complex information about risk and statistics is best depicted in pictures (rather than words); they also went on to note some key statistics that they thought women knew but perhaps did not understand completely. There were also differences in view regarding preferences for the use of concepts like "nine out of ten" and "most".

#### 6.10. Some health practitioners also have a limited understanding of breast cancer, risk factors and the BreastScreen Australia program

While the interviews focused on women's understanding, a number of interview participants also made comments about health practitioners' knowledge of breast cancer, risk factors and the BreastScreen Australia program.

Some of the issues raised appeared to relate to gaps in knowledge about the difference between screening and diagnostic mammography but could also reflect differences in way that screening and diagnostic mammography are funded/delivered across Australia. For example:

A few interview participants told us that GPs do not understand the difference between screening and diagnostic mammograms: some will send a symptomatic woman to the BreastScreen Australia program for a screening mammogram rather than to hospital or private services for a diagnostic work-up, so more information about who is appropriate to refer for screening could be useful.

- Other health practitioners might query why they have not received a diagnostic report following a woman's screening mammogram. This demonstrates a lack of understanding that the screening program's focus is to report on the presence or absence of cancer, at the time of the mammogram.
- Similar to the general population's understanding of the program's parameters, participants told us that GPs often refer women aged under 40 years to the BreastScreen Australia program: some interview participants thought that more information about the eligibility criteria (and rationale) would be helpful.

Some interview participants considered that more information should be provided to GPs about the purpose and parameters of the screening program to address these concerns (although we also note that referral practices might be influenced by the availability of diagnostic mammography and how it is provided/funded, and individual state/territory programs response to the presentation of a symptomatic woman at a screening clinic). Other interview participants wondered if the BSA program should be more proactive and shifting towards providing GPs with more diagnostic information, particularly about non-cancerous lesions (although this was not explored in detail in the interviews).

Health practitioners' understanding of breast cancer risk factors was also raised as an issue; however, this was more in the context of the developing evidence base around some specific risk factors, namely breast density and HRT. Some interview participants noted that these are particularly challenging within the confines of our current knowledge as there are no guidelines or consensus statements about how to manage these risk factors effectively (let alone, communicate this to women).

Some interview participants also queried whether other health practitioners (including pharmacists) could have a role in promoting breast screening participation to women.

### 6.11. Gaps

We asked interview participants to tell us about any specific information gaps or gaps in the evidence base that would be useful to fill. We received a wide range of responses to this question, including proposed epidemiological studies, qualitative research questions, and the provision of specific types of information/resources.

#### 6.11.1. Epidemiological research

Participants identified a small a number of areas where they considered that further epidemiological studies could effectively contribute to better supporting women's knowledge and understanding of breast cancer, breast cancer risk factors, and the breast screening program. Suggestions for epidemiological studies included:

• Research about the incidence of breast cancer in different population groups: for example, Aboriginal and Torres Strait Islander women and Middle Eastern women tend to have a diagnosis of breast cancer at an earlier age than the general Australian population (i.e., in their 40s and 50s): this research could help inform more tailored screening approaches and communications that might benefit more women (eg, inviting them to participate from aged 40 years rather than aged 50 years)

- Research about the link between risk factors and breast cancer (including the combined impact of multiple risk factors) to inform clear and consistent messages about risk factors, and
- Ways to manage overdiagnosis/over-treatment: this could include evidence that supports more conservative management/treatment pathways for low-grade DCIS and other low-risk lesions as well as further information for women about what approaches might be suitable and safe (i.e., moving away from a one-size-fits-all approach to managing abnormalities).

#### 6.11.2. Qualitative research

One overarching point made by a number of interview participants was the need for adequately powered, representative research on Australian women's knowledge and understanding, including asking women about the information they want (and do not want) and the format they want to receive it in. While information does exist (and was provided to us in the form of campaign research or behavioural science research relating to under-screened women), a cohesive, co-designed and comprehensive study does not exist; only some BreastScreen Australia state/territory programs have co-designed resources. That said, it is unclear how much further research is needed or what specific research questions might best address this.

Other potential areas for qualitative research raised by interview participants included:

- increasing understanding about the power of social media to communicate complex clinical information about breast cancer and screening to under-screened women
- how information provided in consumer-focused resources is used and whether it increases knowledge and understanding (and whether this then impacts on screening participation)
- assess CALD community understanding of breast cancer and screening, health literacy levels, and whether translated resources are useful (and if not, what would be useful): this would provide a greater depth of understanding of language and cultural needs to inform the BreastScreen Australia program's approach to developing culturally competent screening information
- deepening our understanding of why some well women prefer to access mammograms in a private, diagnostic setting, including understanding women's views on the differences in services provided through BreastScreen Australia and private practice
- deepening our knowledge about why some women are under-screened, and
- how information needs differ between women of different ages so that information can be tailored accordingly.

#### 6.11.3. Consumer resources about breast cancer, breast cancer risk factors, and screening

Some interview participants suggested specific resources/learning opportunities that might be suitable for consumers in general. Suggestions included providing more:

- evidence-based information about the combined impact of risk factors for women, displayed as a matrix of factors (if the research supports this approach): some suggested creating a robust tool that women can use to assess their risk factors, ensuring breast density is included
- information about the BreastScreen Australia program, including:

- the purpose of the program
- the difference between diagnostic and screening mammograms
- information that will counter existing myths about the program (eg, why we do not use thyroid shields, the purpose of compression, that a mammogram may be uncomfortable but should not be painful, timeliness of receiving results, etc.)
- advice (including digital images/video) explaining the exam process and any recall pathways
- more evidence-based information about preventive measures and modifiable protective factors, and
- information about overdiagnosis/over-treatment (as more options become available) as well as plain English information about treatments and what might be suitable for individual women.

While not a specific gap, some interview participants noted that it would be useful to have some consistent language regarding screening and that this could be developed through a programwide style guide. Related to this, some interview participants said that some jurisdictions do not have the funding available to develop resources. They suggested that a better approach could be to develop resources at the federal level, with the opportunity to co-brand for each state/territory. However, participants also noted that more resources will not necessarily make a big difference to non-attenders and groups who are traditionally under-screeners.

# 6.11.4. Resources for health practitioners about breast cancer, breast cancer risk factors, and screening

Some interview participants suggested specific resources/learning opportunities that might be suitable for health practitioners (including GPs). Suggestions included:

- establishing a stronger clinical consensus/guidance on the management of breast density and HRT use, as well as evidence-based treatment options for breast cancer (noting the need for underpinning epidemiological research as well)
- partnering with other health practitioners to increase their understanding of screening and risk factors for breast cancer, particularly GPs who are International Medical Graduates and who may come from countries where population-based breast screening is not provided, or is provided in a different way to the Australian program model
- encouraging health practitioners to discuss screening in a way that is relevant to the individual (e.g. dependent on age, physical requirements, risk factors) and utilise them to recruit non-attenders into screening, and
- providing resources and education sessions for health practitioners about the BreastScreen Australia program about gender diversity and disability.

#### 7. Gap analysis

From the literature review and interviews with BreastScreen Australia stakeholders, we have confidence that there is a good understanding of how to communicate with women (in general). That is, offering layered, relatable information that resonates with a woman's overall approach to preventive health in a wide range of formats/places where women are looking, and providing this information often given that the cohort of women eligible for and participating in breast-screening changes all the time. As noted by interview participants, every communication strategy works for some women, some of the time: multiple touchpoints and cascades of information are key. Some research has been completed which looks to segment the barriers to screening experienced by under-screened women: this research also offers some further potential areas in which to focus communications if the intention is to increase screening participation. There are of course significant implementation costs and considerations associated with developing and running multi-focal, multi-layered communications campaigns. There may be further opportunities for programs/federal agencies to share in the development and implementation of such activities or to refine existing approaches and roll-out across all programs.

An area consistently identified as challenging by stakeholders was communicating complex clinical information when the science may not provide settled evidence on the direction to take or when there is no clear consensus on what to do. This is problematic for both women who are deciding on whether to participate in breast-screening as well as clinical staff who are providing advice. Key areas where further consensus would be useful are how best to communicate risk in a way that resonates with women, the role of breast density (both as a risk factor for breast cancer and its role in decreasing the sensitivity of mammography), and potential harms associated with over-treatment of detected lesions. No clear consensus on the information that could/should be provided (and by whom) was provided through either the literature review or the stakeholder interviews. However, it is also clear that trusted health advisors (including GPs) also probably require further information about the benefits, harms and limitations of breast-screening in order for them to support women's informed decision-making.

### 7.1. Summary of key gaps by source

Table 10:Gaps by source

Gap	Source		
	Literature	Stocktake	Interviews
General Australian population studies about consumers' understanding of breast cancer, risk factors and screening	Х		
Generally poor understanding of certain risk factors especially regarding family risk, but there was no comprehensive study of consumers' knowledge of each risk factor	Х		Х
There is a lot of well-articulated information on some risk factors but less on others (with relative and absolute risk being difficult to articulate and specific gaps relating to the difference between genetic and family risk)		Х	Х

Gap	Source		
Advice on breast density: it is not clear what Australian women know about this risk factor	Х		Х
There are a lot of myths and misunderstandings about breast cancer, risk factors and mortality (especially potent drivers of non-participation or misunderstanding are combinations of fear and fatalism)	Х		
Understanding about the purpose of screening (ie., mortality reduction, not incidence reduction) is poor and misunderstanding may drive lower prevalent screening	Х		Х
Variable knowledge that screening is for asymptomatic consumers and confusion about interval cancers and accurate understanding of sensitivity/specificity is generally poor	Х		Х
Health practitioner understanding of program parameters is also variable			Х
Understanding of the eligible age range, especially for women aged 40-49 years and 75 years or over	Х		
Limited understanding of overdiagnosis and overtreatment, what might drive this and its importance to screening effectiveness	Х		Х
Information about the limitations of screening is more difficult to find (a lot of available information is very supportive of screening without articulating the risks)		Х	
There is uncertainty about the information that women want but a lot of information is available if women want to find it	X	X	
Cultural-tailored resources are limited.		Х	Х

### 7.2. Where to next?

The literature, stocktake and stakeholder interviews provide some clear directions on 'where to next', which may be considered by the BSA program. In many cases, there are strong exemplars and/or understanding of the messages that are most likely to resonate with consumers.

Items for further exploration include:

- Reviewing existing resources to ensure that these provide trusted information that:
  - reflects evidence-based health advice about breast cancer and screening, including clear advice about the importance of regular screening and when to start (and why this is)

- presents complex information about benefit and modifiable/non-modifiable risk as simply as possible so as to address some of the gaps consistently identified in the literature and the interviews including a clear articulation of limitations of breast screening (including the sensitivity/specificity of mammography and over-treatment issues)
- counters prevailing myths that might stop someone participating in screening or under-screening (including addressing complex concepts like the relative importance of different risk factors, fear and worry that if cancer is detected then nothing can be done, consent and the provision of an overall comfortable, safe experience for consumers: segmentation may help to target messages)
- Reflecting on the best ways to meet the information and communication needs of a complex and large population: there are many different ways to communicate and all will be successful with some women (a one-size fits all is unlikely to result in a significant increase in understanding or drive behaviour change)
- Further research on specific topics including some specific epidemiological topics and further qualitative research to explore the reasons why consumers choose not to participate in screening or who chose to screen less frequently than two-yearly
- Considering the information needs of health practitioners and ensuring that they have access to relevant, topic-based information to help support individuals to understand breast cancer risk and to make informed decisions about participating in screening, including information about the parameters of the BSA program.

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### Annex A: Resources identified in the stocktake

Annex A contains a link to each of the resources identified as part of the stocktake. It is a pointin-time stocktake.: we recognize that organizations prepare updated or new material regularly.

All links are correct at 18 March 2019 but may be subject to change as website owners update and adapt material. Cancer Australia resources are correct at 29 September 2019, when Cancer Australia provided a written update of materials received.

Each resource is organized within the following topic areas:

- About cancer (pages 117 119)
- About risk factors (pages 120 125)
- About breast density (pages 126 127)
- About screening (pages 128 136)
- About the limitations and benefits of screening (page 137)
- About awareness (pages 138 139), and
- Position statements (page 140).

# Resources about breast cancer or symptoms (i.e., general resources)

Organisation	Resource title	URL
Australian Indigenous Health Info	Breast cancer	https://healthinfonet.ecu.edu.au/learn/health-topics/cancer/breast-cancer/
BCNA	About breast cancer	https://www.bcna.org.au/media/2153/bcn849-easy-english-resource-about-breast-cancer-final- 030215Ir.pdf
BreastScreen Australia	About breast cancer	http://cancerscreening.gov.au/internet/screening/publishing.nsf/Content/about-breast-cancer
BreastScreen NSW	About breast cancer	https://www.breastscreen.nsw.gov.au/about-breast-cancer
BreastScreen WA	What is breast cancer?	https://www.breastscreen.health.wa.gov.au/Breast-health/Breast-cancer
BreastScreen Queensland	Aboriginal and Torres Strait Island women	https://www.breastscreen.qld.gov.au/aboriginal-tsi-women.asp
Cancer Australia	Breast cancer: a handbook for Aboriginal and Torres Strait Island health workers	https://canceraustralia.gov.au/system/tdf/publications/breast-cancer-handbook-aboriginal-and-torres- strait-Islanderer-health-workers/pdf/2015_bcat_handbook_2.pdf?file=1&type=node&id=4294
Cancer Australia	Breast cancer fact sheet	https://canceraustralia.gov.au/system/tdf/publications/breast-cancer-fact- sheet/pdf/bckf_breast_cancer_factsheet_51e6410714794.pdf?file=1&type=node&id=3597
Cancer Australia	Types of breast cancer	https://breast-cancer.canceraustralia.gov.au/types
Cancer Australia	What is breast cancer?	https://breast-cancer.canceraustralia.gov.au/
Cancer Australia	What are the symptoms of breast cancer?	https://breast-cancer.canceraustralia.gov.au/symptoms
Cancer Australia	Ductal carcinoma in situ	https://breast-cancer.canceraustralia.gov.au/symptoms/ductal-carcinoma-situ
Cancer Australia	Lobular carcinoma in situ	https://breast-cancer.canceraustralia.gov.au/symptoms/lobular-carcinoma-situ
Cancer Australia	Paget's disease of the nipple	https://breast-cancer.canceraustralia.gov.au/symptoms/paget%E2%80%99s-disease-nipple

Organisation	Resource title	URL
Cancer Australia	Inflammatory breast cancer	https://breast-cancer.canceraustralia.gov.au/symptoms/inflammatory-breast-cancer
Cancer Australia	Locally advanced breast cancer	https://breast-cancer.canceraustralia.gov.au/symptoms/locally-advanced-breast-cancer
Cancer Australia	Metastatic breast cancer	https://breast-cancer.canceraustralia.gov.au/symptoms/metastatic-breast-cancer
Cancer Australia	Breast cancer fact sheet	https://canceraustralia.gov.au/system/tdf/publications/breast-cancer-fact- sheet/pdf/bckf_breast_cancer_factsheet_51e6410714794.pdf?file=1&type=node&id=3597
Cancer Council Australia	Understanding breast cancer	https://www.cancer.org.au/content/about_cancer/ebooks/cancertypes/Understanding_Breast_Cancer_boo klet_July_2018.pdf#_ga=2.86964891.2032863921.1547160141-354780321.1546898334
Cancer Council Australia	Breast cancer	https://www.cancer.org.au/about-cancer/types-of-cancer/breast-cancer/#jump_4
Cancer Council Australia	FAQ	https://www.cancer.org.au/about-cancer/faq.html
Cancer Council ACT	Breast cancer	https://actcancer.org/assets/Publications/Files/edda6a43ea/BreastFSDec2014.pdf
Cancer Council NSW	Breast cancer	https://www.cancercouncil.com.au/breast-cancer/
Cancer Council NT	Breast cancer	https://nt.cancer.org.au/about-cancer/types-of-cancer/breast-cancer.html
Cancer Council WA	Breast cancer	https://www.cancerwa.asn.au/resources/specific-cancers/breast-cancer/
Cancer Council Victoria	Breast cancer overview	https://www.cancervic.org.au/cancer-information/types-of-cancer/breast_cancer/breast-cancer.html
Cancer Council Queensland	Information and symptoms of breast cancer	https://cancerqld.org.au/cancer-information/types-of-cancer/breast-cancer/
Health Direct	Breast cancer	https://www.healthdirect.gov.au/breast-cancer
MyDr	Breast cancer	https://www.mydr.com.au/womens-health/breast-cancer
MyDr	Breast cancer Q and A	https://www.mydr.com.au/womens-health/breast-cancer-q-and-a
National Breast Cancer Foundation	Breast anatomy and how cancer starts	https://nbcf.org.au/about-national-breast-cancer-foundation/about-breast-cancer/what-you-need-to- know/breast-anatomy-cancer-starts/

Organisation	Resource title	URL
NSW Centre for Genetics Education	Breast and ovarian cancer and inherited disposition	http://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-32-breast-and-ovarian- cancer-and-inherited-predisposition
Queensland Health	What is breast cancer?	http://conditions.health.qld.gov.au/HealthCondition/condition/7/51/654/what-is-breast-cancer
South Australia (SA) Health	Breast health	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/bre astscreen+sa/for+clients/breast+health
SA Health	Breast cancer	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+topics/healt h+conditions+prevention+and+treatment/cancer/types+of+cancers/breast+cancer
Tasmanian Health	About breast cancer	https://www.dhhs.tas.gov.au/cancerscreening/population_screening_and_cancer_prevention/breast_scree ning/about_breast_cancer
WA Health	Breast cancer	https://healthywa.wa.gov.au/Articles/A E/Breast-cancer

## **Resources about risk factors**

Organisation	Resource title	URL
BCNA	Risk factors	https://www.bcna.org.au/breast-health-awareness/risk-factors/
BCNA	Family history	https://www.bcna.org.au/media/5992/bcna-fact-sheet-family-history-nov-2017.pdf
BCNA	Position statement: Family history and hereditary breast cancer	https://www.bcna.org.au/about-us/advocacy/position-statements/family-history-and-hereditary-breast- cancer/
BCNA	Family history and hereditary breast cancer background paper	https://www.bcna.org.au/media/2127/family_history_and_hereditary_breast_cancer_background_paper.p df
BreastScreen Australia	BreastScreen Australia	http://cancerscreening.gov.au/internet/screening/publishing.nsf/Content/br-poster/\$File/poster.pdf
BreastScreen Australia	Catching it early BreastScreen brochure (Indigenous resource)	http://cancerscreening.gov.au/internet/screening/publishing.nsf/Content/breast-camp- arrernte/\$File/DL%20brochure%20ARRERNTE.pdf
BreastScreen NSW	Am I at risk?	https://www.breastscreen.nsw.gov.au/about-breast-cancer/am-i-at-risk/
BreastScreen NSW	Breast cancer and family history	https://www.breastscreen.nsw.gov.au/about-breast-cancer/breast-cancer-and-family-history/
BreastScreen NSW	BreastScreen information for women under 40	https://www.breastscreen.nsw.gov.au/media/347856/CANC10019_Brochure_BSInfoU40_R5.pdf
BreastScreen NSW	Breast cancer and family history	https://www.breastscreen.nsw.gov.au/media/347865/CANC10019_Brochure_FamHistory_R3.pdf
BreastScreen Victoria	Trans and gender diverse people	https://www.breastscreen.org.au/get-involved/in-your-community/trans-and-gender-diverse-people/
BreastScreen Victoria	Your breast cancer risk	https://www.breastscreen.org.au/breast-cancer-and-screening/your-breast-cancer-risk/
BreastScreen WA	Family history of breast cancer	https://www.breastscreen.health.wa.gov.au/Breast-health/Family-history-of-breast-cancer
BreastScreen WA	Myths	https://www.breastscreen.health.wa.gov.au/Breast-health/Myths

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Organisation	Resource title	URL
BreastScreen WA	Lifestyle factors	https://www.breastscreen.health.wa.gov.au/Breast-health/Lifestyle-factors
BreastScreen WA	FAQs	https://www.breastscreen.health.wa.gov.au/Breast-health/FAQs
Cancer Australia	Breast cancer risk factors at a glance	https://canceraustralia.gov.au/system/tdf/publications/breast-cancer-risk-factors- glance/pdf/breast_cancer_risk_factors_at_a_glance_0.pdf?file=1&type=node&id=6426
Cancer Australia	Lifestyle risk factors and the primary prevention of cancer	https://canceraustralia.gov.au/publications-and-resources/position-statements/lifestyle-risk-factors-and- primary-prevention-cancer
Cancer Australia	What are the risk factors for breast cancer?	https://breast-cancer.canceraustralia.gov.au/risk-factors
Cancer Australia	Personal risk factors	https://breastcancerriskfactors.gov.au/risk-factors/personal-factors
Cancer Australia	Risk factors	https://breastcancerriskfactors.gov.au/risk-factors/environmental-factors
Cancer Australia	Lifestyle factors	https://breastcancerriskfactors.gov.au/risk-factors/lifestyle-factors
Cancer Australia	Medical history and medication factors	https://breastcancerriskfactors.gov.au/risk-factors/medical-history-and-medications
Cancer Australia	Environmental factors	https://breastcancerriskfactors.gov.au/risk-factors/environmental-factors
Cancer Australia	Modifiable factors	https://breastcancerriskfactors.gov.au/modifiable-factors
Cancer Australia	Protective factors	https://breastcancerriskfactors.gov.au/protective-factors
Cancer Australia	Risk factors at a glance	https://canceraustralia.gov.au/sites/default/files/publications/breast-cancer-risk-factors- glance/pdf/breast_cancer_risk_factors_at_a_glance_0.pdf
Cancer Australia	A review of the evidence	https://canceraustralia.gov.au/sites/default/files/publications/risk-factors-breast-cancer-review-evidence- 2018/pdf/rfbcr_risk_factors_for_breast_cancer_a_review_of_the_evidence_2018_report.pdf

Organisation	Resource title	URL
Cancer Australia	Risk-reducing medication for women at increased risk of breast cancer due to family history	https://canceraustralia.gov.au/system/tdf/publications/rrm-risk-reducing-medication-for-women-at- increased-risk-of-breast-cancer-due-to-family-history_504af03f31630.pdf?file=1&type=node&id=3072
Cancer Australia	Information for women about family history of breast cancer and ovarian cancer	https://canceraustralia.gov.au/system/tdf/publications/information-women-about-family-history-breast- cancer-and-ovarian-cancer/pdf/information_for_women_family_history.pdf?file=1&type=node&id=2973
Cancer Australia	What is FRABOC?	https://canceraustralia.gov.au/clinical-best-practice/gynaecological-cancers/familial-risk-assessment-fra-boc
Cancer Australia	Unproven or unlikely factors	https://breastcancerriskfactors.gov.au/unproven-or-unlikely-factors
Cancer Australia	What you can do	https://breastcancerriskfactors.gov.au/what-you-can-do
Cancer Australia	Cancer risk online assessment tools	https://canceraustralia.gov.au/affected-cancer/check-your-cancer-risk
Cancer Australia	Family history assessment	https://canceraustralia.gov.au/clinical-best-practice/gynaecological-cancers/fra-boc/evaluate
Cancer Australia	Family history and genetic factors	https://breastcancerriskfactors.gov.au/risk-factors/family-history-and-genetic-factors
Cancer Australia	Reproductive factors	https://breastcancerriskfactors.gov.au/risk-factors/reproductive-factors
Cancer Australia	Understanding risk	https://breastcancerriskfactors.gov.au/understanding-risk
Cancer Australia	Cancer risk online assessment tools	https://canceraustralia.gov.au/affected-cancer/check-your-cancer-risk
Cancer Council ACT	Reduce your cancer risk	https://actcancer.org/prevention/information-sheets/reduce-your-cancer-risk/
Cancer Council Queensland	Reducing your cancer risk	https://cancerqld.org.au/cancer-prevention/understanding-risk/
Cancer Council SA	Cut your cancer risk	https://www.cancersa.org.au/assets/images/pdfs/cut-my-risk/CC_Cut_cancer_risk_booklet_Web.pdf
Cancer Council Victoria	Take the lead be breast aware: a guide for Aboriginal women	https://www.cancervic.org.au/downloads/cpc/breast/breast-awareness-aboriginal-brochure.pdf

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Organisation	Resource title	URL
Cancer Council Victoria	Familial breast cancer	https://www.cancervic.org.au/cancer-information/genetics-and-risk/familial-breast-cancer
Health Direct	What causes breast cancer?	https://www.healthdirect.gov.au/what-causes-breast-cancer
Health Direct	Breast cancer prevention	https://www.healthdirect.gov.au/breast-cancer-prevention
MyDr	Breast cancer: early diagnosis is the key	https://www.mydr.com.au/womens-health/breast-cancer-early-diagnosis-is-the-key
National Breast Cancer Foundation	Breast cancer risk factors you can't change	https://nbcf.org.au/about-national-breast-cancer-foundation/about-breast-cancer/what-you-need-to- know/risk-prevention/how-research-is-making-a-difference-to-breast-cancer-risk/
National Breast Cancer Foundation	Breast cancer risk factors that can't be changed	https://nbcf.org.au/about-national-breast-cancer-foundation/about-breast-cancer/what-you-need-to- know/risk-prevention/risk-factors-that-cant-be-changed/
National Breast Cancer Foundation	Breast cancer myths and facts	https://nbcf.org.au/about-national-breast-cancer-foundation/about-breast-cancer/what-you-need-to- know/detection/breast-cancer-myths/
NSW Health Cancer Institute	Higher risk areas for breast cancer in NSW	https://www.cancer.nsw.gov.au/how-we-help/screening-and-early-detection/breast-cancer- screening/higher-risk-areas-for-breast-cancer-in-nsw
NSW Health Cancer Institute	Alcohol and cancer	https://www.cancer.nsw.gov.au/how-we-help/cancer-prevention/lifestyle-cancer-risks/alcohol-awareness
Pink Hope	Know your risk tool	https://pinkhope.org.au/know-your-risk/
Pink Hope	Breast cancer risk factors	https://pinkhope.org.au/breast-cancer-risk-factors/
Pink Hope	Understand your risk	https://pinkhope.org.au/am-i-at-risk/understand-your-risk/
Pink Hope	Lifestyle factors	https://pinkhope.org.au/am-i-at-risk/lifestyle-factors/
Queensland Health	Breast cancer screening and prevention	https://www.qld.gov.au/health/conditions/screening/cancer/breast
Queensland Health	Risk of breast cancer in Australian women	https://www.health.qld.gov.au/data/assets/pdf_file/0031/443587/risk-breast-cancer-factsheet.pdf

Organisation	Resource title	URL
Queensland Health	Breast cancer risk factors	http://conditions.health.qld.gov.au/HealthCondition/condition/7/51/214/breast-cancer-risk-factors
SA Health	Family history	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/bre astscreen+sa/for+clients/breast+health+-+breastscreen+sa/family+history
SA Health	Risk assessment tool - calculate your risk	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/bre astscreen+sa/for+clients/breast+health+-+breastscreen+sa/risk+assessment+tool+-+calculate+your+risk
Tasmanian Health	Prevention, screening and early detection	https://www.dhhs.tas.gov.au/cancerscreening/population_screening_and_cancer_prevention/about_cance r/prevention,_screening_and_early_detection
Tasmanian Health	Risk factors	https://www.dhhs.tas.gov.au/cancerscreening/population_screening_and_cancer_prevention/about_cance r/risk_factors
Tasmanian Health	What does it mean for me if someone in my family has had breast cancer?	https://www.dhhs.tas.gov.au/data/assets/pdf_file/0010/214687/BreastScreen_Family_History.pdf
WA Health	What are the risk factors for breast cancer?	https://healthywa.wa.gov.au/Articles/U_Z/What-are-the-risk-factors-for-breast-cancer
WA Health	Diethylstilbestrol (DES) and cancer	https://healthywa.wa.gov.au/Articles/A_E/Diethylstilbestrol-DES-and-cancer
Westmead BCI	Diet, Lifestyle and Breast Cancer Risk	https://www.bci.org.au/breast-cancer-information/fact-sheets/diet-lifestyle-breast-cancer-risk/
Westmead BCI	Family history of breast cancer	https://www.bci.org.au/breast-cancer-information/fact-sheets/family-history-breast-cancer/
Westmead BCI	Managing your risk of breast and ovarian cancer	https://www.bci.org.au/breast-cancer-information/fact-sheets/managing-risk-breast-ovarian- cancer/

# Resources about breast density

Organisation	Resource title	URL
Be Dense Aware	Mammographic density position statement	http://www.bedenseaware.com/position-statement/
Be Dense Aware	Myth busting	http://www.bedenseaware.com/myth-busting/
Be Dense Aware	What is breast density?	http://www.bedenseaware.com/what-is-breast-density/
Be Dense Aware	What does it mean for me?	http://www.bedenseaware.com/what-does-it-mean-for-me/
Be Dense Aware	Breast density 101	http://bedenseaware.com/wp-content/uploads/2018/03/bda-breast-density-101.pdf
BreastScreen NSW	Breast density: Overview	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/screening-limitations/breast-density
BreastScreen NSW	Potential limitations of mammograms	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/potential-limitations-of- mammograms/
BreastScreen Victoria	Breast density	https://www.breastscreen.org.au/breast-cancer-and-screening/screening-methods-and-diagnosis/breast- density/
BreastScreen WA	Dense breasts	https://www.breastscreen.health.wa.gov.au/Breast-screening/Dense-breasts
BreastScreen WA	FAQs	https://www.breastscreen.health.wa.gov.au/Breast-health/FAQs
Health Direct	Breast cancer diagnosis	https://www.healthdirect.gov.au/breast-cancer-diagnosis
INFORMD	Frequently Asked Questions	https://www.informd.org.au/faqs.html
National Breast Cancer Foundation	Breast density	https://nbcf.org.au/about-national-breast-cancer-foundation/about-breast-cancer/what-you-need-to- know/risk-prevention/breast-density-2/
Pink Hope	Breast density: the state of play in Australia	https://pinkhope.org.au/breast-density-the-state-of-play-in-australia/
Pink Hope	Know your body	https://pinkhope.org.au/am-i-at-risk/your-body-and-your-doctor/know-your-body/

Organisation	Resource title	URL
SA Health	Breast health	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+s ervices/breastscreen+sa/for+clients/breast+health
SA Health	Breast density information for consumers	https://www.sahealth.sa.gov.au/wps/wcm/connect/6e1a80804e78310ebd28fdc09343dd7f/Bre

## Resources about screening

Organisation	Resource title	URL
ACT Health	Breast screening	https://www.health.act.gov.au/services-and-programs/women-youth-and-children/womens-health/breast- screening
BCNA	Breast cancer screening	https://www.bcna.org.au/breast-health-awareness/breast-cancer-screening/
BCNA	Position statement: BreastScreen Australia	https://www.bcna.org.au/about-us/advocacy/position-statements/breastscreen-australia/
BreastScreen Australia	BreastScreen and You: Information about mammography screening	http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/194B6BD076D4A6F9CA257 D71007BF9F5/\$File/Breastscreen Brochure March WEB.pdf
BreastScreen Australia	About breast screening	http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/about-breast-screening
BreastScreen Australia	The screening process	http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/the-screening-process- breast
BreastScreen Australia	About the program	http://cancerscreening.gov.au/internet/screening/publishing.nsf/Content/about-the-program
BreastScreen Australia	You're Invited BreastScreen Brochure	http://cancerscreening.gov.au/internet/screening/publishing.nsf/Content/5DB6070513256DB8CA25825C00 064B49/\$File/Youre-Invited-Breastscreen-Brochure-DL-4pp.pdf
BreastScreen NSW	About screening mammograms	https://www.breastscreen.nsw.gov.au/about-screening-mammograms
BreastScreen NSW	Am I eligible for a mammogram?	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/am-i-eligible-for-a-mammogram/
BreastScreen NSW	Benefits of screening mammograms	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/benefits-of-screening- mammograms/
BreastScreen NSW	Information for Aboriginal women	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/information-for-aboriginal-women/

Organisation	Resource title	URL
BreastScreen NSW	Information in other languages	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/information-in-other-languages/
BreastScreen NSW	About screening mammograms: FAQs	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/about-screening-mammograms- faqs/#whyisearlydetectionimportant
BreastScreen NSW	Detecting breast cancer early is vital	https://www.breastscreen.nsw.gov.au/media/347859/CANC10019 Brochure DetectingBCearly R4.pdf
BreastScreen NSW	Not in my family'	https://www.breastscreen.nsw.gov.au/campaigns/not-in-my-family
BreastScreen NSW	Breast implants and breast screening	https://www.breastscreen.nsw.gov.au/media/362687/canc10019_brochure_implantinfo.pdf
BreastScreen NSW	Information about breast screening for Aboriginal women	https://www.breastscreen.nsw.gov.au/media/310175/info-canc10011_breast_fact-sheet_r3.pdf
BreastScreen NSW	Have a breast screen every two years it could save your life	https://www.breastscreen.nsw.gov.au/media/338677/2-years-canc10011_breast_dlflyer_r3.pdf
BreastScreen NSW	It's time for your next mammogram	https://www.breastscreen.nsw.gov.au/media/347868/CANC10019 Brochure ItsTime R3.pdf
BreastScreen Queensland	Who is eligible	https://www.breastscreen.qld.gov.au/who-is-eligible.asp
BreastScreen Queensland	l'm under 40	https://www.ordermax.com.au/ProductDisplay.aspx?Product=4300750
BreastScreen Queensland	Wise women your guide to having a breast screen	https://www.breastscreen.qld.gov.au/breastscreen/downloads/WiseWomenBooklet.pdf
BreastScreen Queensland	The simple facts	https://www.ordermax.com.au/ProductDisplay.aspx?Product=4300432
BreastScreen Queensland	Culturally and linguistically diverse women	https://www.breastscreen.qld.gov.au/cultural-women.asp
BreastScreen Victoria	What is a breast screen?	https://www.breastscreen.org.au/what-happens/what-is-a-breast-screen/

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Organisation	Resource title	URL
BreastScreen Victoria	Should I be screened?	https://www.breastscreen.org.au/what-happens/should-i-be-screened/
BreastScreen Victoria	Age groups	https://www.breastscreen.org.au/what-happens/should-i-be-screened/age-groups/
BreastScreen Victoria	Your stories	https://www.breastscreen.org.au/what-happens/womens-stories/
BreastScreen Victoria	Screening methods and diagnosis	https://www.breastscreen.org.au/breast-cancer-and-screening/screening-methods-and-diagnosis/
BreastScreen Victoria	Is BreastScreen for you?	https://clara.breastscreen.org.au/intranet/documents/21/111/BSV_Is_BreastScreen_For_You_ENG.pdf
BreastScreen Victoria	Screening for women with disabilities	https://clara.breastscreen.org.au/intranet/documents/21/117/BSV_Screening_for_women_with_disabilities .pdf
BreastScreen Victoria	Breast screening with implants	https://clara.breastscreen.org.au/intranet/documents/21/354/BSV Implants fact sheet.pdf
BreastScreen Victoria	Women with a previous diagnosis of breast cancer	https://clara.breastscreen.org.au/intranet/documents/21/356/BSV Past history fact sheet.pdf
BreastScreen Victoria	Family history of breast cancer and screening	https://clara.breastscreen.org.au/intranet/documents/21/107/BSV Family history of breast cancer and <u>Screening.pdf</u>
BreastScreen Victoria	What is the difference between a screening and a diagnostic mammogram?	https://clara.breastscreen.org.au/intranet/documents/21/106/BSV %20Difference between screening an d_diagnostic_%20mammogram.pdf
BreastScreen Victoria	Breast/chest screening for trans and gender diverse people	https://clara.breastscreen.org.au/intranet/documents/21/1164/BSV Trans and Gender Diverse People.p df
BreastScreen WA	About screening mammograms	https://www.breastscreen.health.wa.gov.au/Breast-screening/About-screening-mammograms
BreastScreen WA	Women under 40	https://www.breastscreen.health.wa.gov.au/Breast-screening/Women-under-40
BreastScreen WA	Women over 75	https://www.breastscreen.health.wa.gov.au/Breast-screening/Women-over-75

Organisation	Resource title	URL
BreastScreen WA	Women with breast implants	https://www.breastscreen.health.wa.gov.au/Breast-screening/Women-with-breast-implants
BreastScreen WA	Women with a disability	https://www.breastscreen.health.wa.gov.au/Breast-screening/Women-with-a-disability
BreastScreen WA	Information for consumers on breast tomosynthesis	https://www.breastscreen.health.wa.gov.au/~/media/B544EDB123C2414F9F9BDA31435A7CA5.ashx
BreastScreen WA	Breast screening information	https://www.breastscreen.health.wa.gov.au/~/media/BSWA/Fact%20Sheets/CaLD/Breast%20Sreening%20I nformation/HP000373_ENGLISH_BSWABreast%20ScreeningInformationFactSheet.pdf
BreastScreen WA	When did you last have a free screening mammogram?	https://www.breastscreen.health.wa.gov.au/~/media/C66D8986C5EB41F181DFF117D063E003.ashx
BreastScreen WA	Beat breast cancer have a free x-ray	https://www.breastscreen.health.wa.gov.au/~/media/86791639A3A943BD899022D4882C148F.ashx
Cancer Australia	Looking after your breasts	https://canceraustralia.gov.au/system/tdf/publications/womens-business-workshop-looking-after-your- breasts-flyer/pdf/2016_atsi_labb_breast_flyer.pdf?file=1&type=node&id=4362
Cancer Australia	Breast changes	https://www.youtube.com/watch?v=iCvFMTJgD1I&has_verified=1_
Cancer Australia	Breast cancer won't wait. Everything else can.	https://canceraustralia.gov.au/sites/default/files/publications/breast-cancer-wont- wait/pdf/cwwb_bc_flyer.pdf
Cancer Australia	Find it early and survive	https://www.youtube.com/watch?v=HVuVcNZsLjE
Cancer Australia	Looking after your breasts - Find breast cancer early and survive	https://canceraustralia.gov.au/atsi/breastcancer
Cancer Australia	Lots to live for	https://www.youtube.com/watch?v=cLftpu7KI_M
Cancer Australia	Looking after your breasts - Find breast cancer early and survive	https://canceraustralia.gov.au/sites/default/files/publications/womens-business-workshop-looking-after- your-breasts-flyer/pdf/2016 atsi labb breast flyer.pdf

Organisation	Resource title	URL
Cancer Australia	Looking after your breasts - What every Aboriginal and Torres Strait Islander woman should know	https://canceraustralia.gov.au/sites/default/files/publications/looking-after-your-breasts- flyer/pdf/2013_atsi_dl_flyer_looking_after_your_breasts.pdf
Cancer Council Australia	Get checked - women	https://www.cancer.org.au/preventing-cancer/reduce-your-risk/get-checked-women.html
Cancer Council Australia	Mammogram	https://www.cancer.org.au/about-cancer/types-of-cancer/breast-cancer/mammogram.html
Cancer Council Australia	Breast cancer screening	https://www.cancer.org.au/about-cancer/early-detection/screening-programs/breast-cancer- screening.html
Cancer Council ACT	Cancer screening	https://actcancer.org/prevention/cancer-screening/
Cancer Council NSW (International links include American Cancer Society, Cancer Research UK, Macmillan Cancer Support UK)	Breast cancer screening	https://www.cancercouncil.com.au/964/uncategorized/breast-cancer-screening/
Cancer Council NT	Early detection of breast cancer	https://nt.cancer.org.au/Early-detection-of-breast-cancer-2014-revised.pdf
Cancer Council NT	Breast cancer screening	https://nt.cancer.org.au/about-cancer/early-detection/screening-programs/breast-cancer-screening.html
Cancer Council Queensland	Screening service	https://cancergld.org.au/cancer-prevention/early-detection/screening-service/#breastscreen-australia-1
Cancer Council SA	Cancer screening	https://www.cancersa.org.au/assets/images/pdfs/cut-my- risk/PrevScre%20Cancer%20Screening%20DL%20Brochure_FA-Web.pdf
Cancer Council WA	Early detection	https://www.cancerwa.asn.au/prevention/earlydetection/
Cancer Council WA	Unproven breast imaging technologies - the facts	https://www.cancerwa.asn.au/resources/2017-02-15-unproven-breast-imaging-fact-sheet.pdf

Organisation	Resource title	URL
Health Direct	Mammography	https://www.healthdirect.gov.au/mammography
Health Direct	Breast cancer diagnosis	https://www.healthdirect.gov.au/breast-cancer-diagnosis
MyDr	Mammograms	https://www.mydr.com.au/womens-health/mammograms
myVMC	Early detection of breast cancer	https://www.myvmc.com/investigations/early-detection-of-breast-cancer/
myVMC	Mammography (breast imaging)	https://www.myvmc.com/investigations/mammography-breast-imaging/
National Breast Cancer Foundation	Detection and screening methods	https://nbcf.org.au/about-national-breast-cancer-foundation/about-breast-cancer/what-you-need-to- know/detection/detection-and-screening-methods/
NSW Health Cancer Institute	Breast cancer screening	https://www.cancer.nsw.gov.au/how-we-help/screening-and-early-detection/breast-cancer-screening
NSW Health Cancer Institute	Why breast screening is important	https://www.cancer.nsw.gov.au/how-we-help/screening-and-early-detection/breast-cancer-screening/why- is-breast-screening-important
NSW Health Cancer Institute	Who needs to screen?	https://www.cancer.nsw.gov.au/how-we-help/screening-and-early-detection/breast-cancer-screening/who- needs-to-screen
NSW Health Cancer Institute	BreastScreen NSW service	https://www.cancer.nsw.gov.au/how-we-help/screening-and-early-detection/breast-cancer- screening/overview-about-breastscreen-nsw
NT Health	Breast cancer	https://nt.gov.au/wellbeing/cancer-services/breast-cancer
NT Health	Cancer and remote residents	https://nt.gov.au/wellbeing/remote-health/cancer-and-remote-residents
NT Health	BreastScreen NT	https://nt.gov.au/wellbeing/cancer-services/breastscreennt
Pink Hope	Screening	https://pinkhope.org.au/am-i-at-risk/risk-management/screening/

Organisation	Resource title	URL
Pink Hope	Screening FAQs	https://pinkhope.org.au/screening-faqs/
Pink Hope	MRI breast screening	https://pinkhope.org.au/mri-breast-screening/
Pink Hope	Ultrasound for breast screening	https://pinkhope.org.au/ultrasound-for-breast-screening/
Pink Hope	Breast screening: what's right for me?	https://pinkhope.org.au/breast-screening-whats-right-for-me/
SA Health	What is a breast screen?	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/bre astscreen+sa/for+clients/what+is+a+breast+screen
SA Health	Who can have a breast screen?	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/bre astscreen+sa/for+clients/what+is+a+breast+screen+-+breastscreen+sa/why+should+i+have+it
SA Health	Frequently Asked Questions	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/bre astscreen+sa/for+clients/what+is+a+breast+screen+-+breastscreen+sa/frequently+asked+questions
SA Health	Why should I have a breast screen?	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/bre astscreen+sa/for+clients/what+is+a+breast+screen+-+breastscreen+sa/why+should+i+have+it
SA Health	Do you know about free breast cancer screening?	https://www.sahealth.sa.gov.au/wps/wcm/connect/0dc122804fb74da1ba33ff5fa07ddff7/BSSA_Brochure_D o+you+know+about+free+breast+cancer+screening_2016.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE- 0dc122804fb74da1ba33ff5fa07ddff7-m3IZP50
SA Health	Have a free breast screen every two years	https://www.sahealth.sa.gov.au/wps/wcm/connect/966e70804bc153cb9334db501ddc6524/BSSA0001+A4- DL+Brochure+Web.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE- 966e70804bc153cb9334db501ddc6524-mttSFuT
SA Health	After your breast screen appointment	https://www.sahealth.sa.gov.au/wps/wcm/connect/ee89668040acfc0e99ab9b9d26b921e1/BSSA_Brochure After+your+breast+screen_2012.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE- ee89668040acfc0e99ab9b9d26b921e1-m3m6tZd

Organisation	Resource title	URL
SA Health	Screening for women with breast implants and other medical devices	https://www.sahealth.sa.gov.au/wps/wcm/connect/59457f8040acfaf3998a9b9d26b921e1/BSSA_Brochure Screening+with+implants_2013.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE- 59457f8040acfaf3998a9b9d26b921e1-msqggQF
SA Health	Reduce your risk	https://www.sahealth.sa.gov.au/wps/wcm/connect/9d684a0040acef6198d49b9d26b921e1/BSSA_Postcard Reducing+your+risk_2016.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE- 9d684a0040acef6198d49b9d26b921e1-m3m6uAh
SA Health	You're invited	https://www.sahealth.sa.gov.au/wps/wcm/connect/f202b20040acf8dd99489b9d26b921e1/BSSA_Postcard Youre+Invited_2016.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE202b20040acf8dd99489b9d26b921e1 -m3m6ujb
SA Health	A guide to breast health	https://www.sahealth.sa.gov.au/wps/wcm/connect/6ca60c804faaf3a28f30cf5fa07ddff7/BSSA_Booklet_A+G uide+to+Breast+Health.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE- 6ca60c804faaf3a28f30cf5fa07ddff7-msq8sKj
SA Health	Screening for Aboriginal women	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/bre astscreen+sa/for+clients/screening+for+aboriginal+women
Tasmanian Health	Breast screening	https://www.dhhs.tas.gov.au/cancerscreening/population_screening_and_cancer_prevention/breast_scree ning
Tasmanian Health	BreastScreen Australia poster	http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/br-poster/\$File/poster.pdf
Victoria Health	Breast cancer screening	https://www2.health.vic.gov.au/public-health/population-screening/cancer-screening/breast-cancer- screening
WA Health	Screening mammography with BreastScreen WA	https://healthywa.wa.gov.au/Articles/S_T/Screening-mammography-with-BreastScreen-WA
Westmead BCI	Breast screening	https://www.bci.org.au/patient-information/breast-screening/

## Resources about the limitations and benefits of screening

Organisation	Resource title	URL
BreastScreen Australia	Frequently Asked Questions	http://cancerscreening.gov.au/internet/screening/publishing.nsf/Content/frequently-asked-questions
BreastScreen NSW	Potential limitations of mammograms	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/potential-limitations-of- mammograms/
BreastScreen NSW	Over diagnosis	https://www.breastscreen.nsw.gov.au/about-screening-mammograms/screening-limitations/overdiagnosis
BreastScreen Queensland	Benefits and harms	https://www.breastscreen.qld.gov.au/benefits-risks.asp
BreastScreen Victoria	Your screening choice	https://www.breastscreen.org.au/what-happens/should-i-be-screened/
BreastScreen Victoria	Radiation	https://www.breastscreen.org.au/breast-cancer-and-screening/screening-methods-and-diagnosis/radiation/
BreastScreen Victoria	Over diagnosis	https://www.breastscreen.org.au/breast-cancer-and-screening/screening-methods-and- diagnosis/overdiagnosis/
BreastScreen WA	Benefits and harms	https://www.breastscreen.health.wa.gov.au/Breast-screening/Benefits-and-harms
BreastScreen WA	Radiation	https://www.breastscreen.health.wa.gov.au/Breast-screening/Radiation
Cancer Australia	Overdiagnosis from mammographic screening	https://canceraustralia.gov.au/publications-and-resources/position-statements/overdiagnosis- mammographic-screening

#### **Resources about awareness**

Organisation	Resource title	URL
BCNA	Position statement: Early detection information	https://www.bcna.org.au/about-us/advocacy/position-statements/early-detection-information/
BreastScreen NSW	Signs and symptoms	https://www.breastscreen.nsw.gov.au/about-breast-cancer/signs-and-symptoms
BreastScreen Queensland	Questions and answers	https://www.breastscreen.qld.gov.au/faq.asp
BreastScreen Queensland	Breast health	https://www.breastscreen.qld.gov.au/breast-health.asp
BreastScreen Victoria	Signs and symptoms	https://www.breastscreen.org.au/breast-cancer-and-screening/symptoms-of-breast-cancer/
BreastScreen WA	Breast awareness	https://www.breastscreen.health.wa.gov.au/Breast-health/Breast-awareness
Cancer Australia	Breast cancer awareness postcard - knowledge is never out of fashion	https://canceraustralia.gov.au/system/tdf/publications/breast-cancer-awareness-postcard-knowledge- never-out-fashion/pdf/2016 bcam bcpc postcard.pdf?file=1&type=node&id=5206
Cancer Australia	Breast cancer awareness	https://breast-cancer.canceraustralia.gov.au/awareness
Cancer Australia	Breast cancer awareness	https://canceraustralia.gov.au/atsi/breastcancer
Cancer Council Australia	Early detection of breast cancer	https://www.cancer.org.au/content/pdf/Factsheets/Early-detection-of-breast-cancer-2013-revised.pdf
Cancer Council Australia	What every Aboriginal and Torres Strait Islander woman should know #1	https://www.youtube.com/watch?v=3ObEUrza9Zw&feature=youtu.be&list=PLgeVuGloYeWmfq5O00DNgnb MAKvWYg1HV
Cancer Council ACT	Early detection	https://actcancer.org/prevention/early-detection/
Cancer Council NT	Get checked - women	https://nt.cancer.org.au/preventing-cancer/reduce-your-risk/get-checked-women.html
Cancer Council SA	Breast awareness for all women	https://www.cancersa.org.au/assets/images/pdfs/cut-my- risk/2018%20PrevWom_Breast_Awareness_Apr2018_FA_Web.pdf

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Organisation	Resource title	URL
Cancer Council SA	Finding breast cancer early	https://www.cancersa.org.au/information/a-z-index/finding-breast-cancer-early?path=/information/i-want- to-cut-my-cancer-risk/finding-cancer-early/finding-breast-cancer-early
Cancer Council Tasmania	Get checked: early detection	http://www.cancertas.org.au/prevent-cancer/checkups-and-screening/
Cancer Council Victoria	Breast awareness and screening	https://www.cancervic.org.au/preventing-cancer/attend-screening/breasts-health/breast-screen
Cancer Council WA	Women and cancer	https://www.cancerwa.asn.au/resources/2018-07-17-women-and-cancer-DL-web-version.pdf
Cancer Council WA	Breast awareness for all women	https://www.cancerwa.asn.au/resources/2018-10-10-BREAST-AWARENESS-DL.pdf
Health Direct	Breast cancer awareness	https://www.healthdirect.gov.au/breast-cancer-awareness
McGrath Foundation	Breast health understanding	https://www.mcgrathfoundation.com.au/about/what-we-do/breast-awareness/
NSW Health	Breast Health	https://www.health.nsw.gov.au/disability/Publications/being-a-healthy-woman-63-68.pdf
Pink Hope	Feel your boobies	https://pinkhope.org.au/wp-content/uploads/2015/07/Feel-your-boobies_landscape3.pdf
Pink Hope	Know your body	https://pinkhope.org.au/am-i-at-risk/your-body-and-your-doctor/know-your-body/
WA Health	How can I look out for breast cancer?	https://healthywa.wa.gov.au/Articles/F I/How-can-I-look-out-for-breast-cancer
Westmead BCI	Breast health	https://www.bci.org.au/breast-cancer-information/fact-sheets/breast-health/
### **Position statements**

Organisation	Resource title	URL
Cancer Australia	Early detection of breast cancer (position statement)	https://canceraustralia.gov.au/publications-and-resources/position-statements/early-detection-breast- cancer
Cancer Australia	Position statement: Overdiagnosis from mammographic screening	https://canceraustralia.gov.au/publications-and-resources/position-statements/overdiagnosis- mammographic-screening
SA Health	Position statements	https://www.sahealth.sa.gov.au/wps/wcm/connect/public%20content/sa%20health%20internet/health%20 services/breastscreen%20sa/about%20breastscreen%20sa/position%20statements

# ANNEX B Semi-structure stakeholder interview questions

## Women's knowledge: understanding and influencing

### **Breast cancer risk factors**

- 1. Are there any specific breast cancer risk factors that Australian women understand well?
- 2. Are there any specific breast cancer risk factors that Australian women understand poorly or not at all?
- 3. What are your views on how best to effectively influence or improve women's understanding of breast cancer risk factors?

#### Benefits and risks of breast screening

- 4. Are there specific benefits or risks of screening that Australian women understand well?
- 5. Are there any specific benefits or risks of screening that Australian women understand poorly or not at all?
- 6. What are your views on how best to effectively influence or improve women's understanding of breast screening?

#### Screening intention and behaviour

- 7. Do you have any insights about how women's knowledge, perceptions and beliefs impact on their attitude towards participating in breast screening?
- 8. Have you undertaken any work which explores the relationship between knowledge of risk factors/screening benefits and risks and screening intention and behaviour?

### Awareness of reports or data about Australian women's knowledge

- 9. Has your organisation commissioned or completed any work/research about the following:
  - a. Women's understanding of breast cancer risk factors?
  - b. Women's understanding of the benefits and risks of screening?
  - c. How understanding of risk factors/benefits and risks of screening influences screening intention and behaviour?
  - d. Needs and preferences about how services communicate complex clinical information about risks and benefits?

### Women's resource/communications needs

10. How do you think women like to be informed about breast cancer risk, and the benefits and risks of breast screening?

11. What things are important when communicating complex clinical information about breast cancer risk to women? About the benefits and risks of screening?

# Gaps and next steps

12. Are there any specific information gaps or gaps in the evidence base that would be useful to fill?

## ANNEX C Interview participants

We met with stakeholders from the following organisations:

- BreastScreen New South Wales
- BreastScreen Northern Territory
- BreastScreen Queensland
- BreastScreen South Australia
- BreastScreen Tasmania
- BreastScreen Victoria
- BreastScreen Western Australia
- Cancer Australia