The Social Construction of Choice within Screening Mammography: Implications for Policy, Practice, and Communication

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October, 2020

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This thesis is presented for the Degree of

Doctor of Philosophy

of

Curtin University

Declaration

To the best of my knowledge and belief, this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university. The research presented and reported in this thesis was conducted in accordance with the National Medical Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) — updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number HRE2016-0214 (Appendix A).

Kristen Seaman

23 October 2020

Abstract

There is increasing support in ensuring cisgender women make an informed decision before participating in biennial screening mammography. Efforts to support women in making an informed decision have been shaped by contention in research literature regarding the benefit/harm ratio posed to asymptomatic women by screening mammography, and the biomedical conceptualisation of informed consent. As such, efforts to support women have included analyses of print and web media to assess accuracy of information, the development of decision-aids, and explorations into the barriers of shared decision-making during the clinical encounter. While important, they may be insufficient in supporting women to make an informed decision—they neglect the role of socio-cultural, historical, and political processes on women's willingness to engage in screening mammography. Research has shown that screening mammography participation is associated with social and moral obligations. For this reason, I adopted a feminist-relational framework of informed decision-making within this research—informed choice. The feminist-relational perspective enabled me to explore and critically consider, if and how, socio-cultural processes influence opportunities for women to make an informed choice regarding their participation in BreastScreen Australia. Therefore, the overarching aim of the research project was to explore, through interrelated studies, if cisgender women were provided opportunities to make informed decisions in the breast screening context.

Study 1 (Chapter 3) was the first study in the research project, and the first systematic review of women's knowledge of screening mammography. Included studies ($N = 35$) were published/completed between 1992 and 2017, comprised of varying methodologies, and were from member countries of the International Cancer Screening Network—Breast Cancer Division. The studies were analysed using a narrative synthesis and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis. The results of the review indicated that women tend to overestimate the benefits of screening and underestimate the harms. More specifically, some topics (i.e., radiation and commencement age) appeared well understood by women, while other topics (i.e., cessation age, overdiagnosis, and mortality reduction) were not. In addition, through the variability identified in knowledge measures within included studies, the review highlighted the lack of consensus within the field regarding what women should know. The ambiguity regarding what women should know about screening mammography, in order to be categorised as knowledgeable, led me to question the utility of a definition of informed consent wherein knowledge possession was privileged.

Study 2 (Chapter 4) was a qualitative study that aimed to explore how cisgender women discussed screening mammography, explore the subject positions (i.e., ways of being) made available through participants' discourse, and critically consider the implications to opportunities for informed choice. Sixteen participants were recruited aged between 44 and 72 years. Eleven participants attended biennial screening, while five participants attended less frequently, or not at all. The data was gathered via semi-structured face-to-face interviews and analysed using Foucauldian discourse analysis (FDA). The participants constructed screening mammography as either a helpful or harmful practice. Three subject positions were identified within participant's discourse—The Responsible Woman, a woman who attends biennial screening; the Irresponsible Woman, a woman who does not attend screening, and the Judicious Woman, a woman who engages in alternate breast health behaviours (e.g., maintaining a healthy diet and weight). All women's discourse reproduced ideas about risk; that responsible women take action to mitigate their risk of dying or disease. However, the results suggest that screening mammography is the most "correct" form of breast health, and as such, value-laden ways of being were constituted. Another important finding was the

variability identified in women's preferences for, and experiences of, shared decision-making with general practitioners (GPs).

Study 3 (Chapter 5) was a critical analysis of Australian mass media (i.e., television news channels, and national/state newspapers) produced between 2017 and 2019. The form of mass media analysed (i.e., television news channels, and National /state newspapers) was informed by participants in Study 2 (Chapter 4). The analysis used FDA and aimed to identify the subject positions made available in breast screening discourse produced by mass media, and critically consider the implications to opportunities for informed choice. The data was systematically collected and comprised 61 articles published in 11 state/national newspapers, and 8 broadcasts aired by four Australian free-to-air networks. Three subject positions were identified—the Vulnerable Attendee, a woman vulnerable of developing/dying from breast cancer; the Overdue Attendee, a woman who intends to screen, but is currently experiencing barriers in doing so, and the Obligated Attendee, a woman who feels grateful for the provision of BreastScreen Australia and screens in solidary with other deserving women. Inherent in all subject positions was an expectation that a woman would engage in screening—whether that be now, or later.

Study 4 (Chapter 6) was a qualitative study that aimed to identify the discourses used by GPs when discussing screening mammography with cisgender female patients and critically consider the implications to shared decision-making practices and informed choice. GPs were identified as relevant health professionals to interview by participants in Study 2 (Chapter 4). Data was collected from 12 GPs via semi-structured interviews, conducted either face-to-face or by telephone, and analysed using FDA. Six discourses were identified—Science, Government, Risk, Public Health, Professional Responsibility, and Paternalism, which indicated that GPs' shared decision-making practices and recommendations are influenced by more than scientific evidence alone. Another key finding related to the

identification of social and structural barriers to shared decision-making that are encountered by some GPs (e.g., belief that educated woman already know to screen, time constraints). Social barriers (i.e., socio-cultural processes) meant that women aged 50-74 years, and women perceived as less educated, were afforded fewer opportunities to engage in shared decision-making than woman aged 40-49 years or 74 and over.

The findings of the four interrelated studies indicate that opportunities for cisgender women to make an informed choice regarding their participation in BreastScreen Australia are limited; screening mammography is not constructed as a choice within the discourses used by many women and GPs, or any discourses used by mass media, while opportunities for shared decision-making during the clinical encounter appear hindered by socio-cultural processes and structural barriers. The findings of the research project make a substantial contribution to identifying processes that facilitate and hinder informed decision-making in the breast screening context. In doing so, the research findings underscore the previously identified need to reconceptualise informed decision-making from a practice rooted in biomedical understandings of autonomy, commonly termed informed consent, and instead adopt a feminist-relational framework and the concept of informed choice.

Acknowledgments

First, I would like to thank all the individuals who participated in this research and/or facilitated recruitment. Thank you for speaking with me about you experiences and for sharing my project with your peers, friends, and family.

To my research supervisors, Associate Professor Lauren Breen, Dr Peta Dzidic and, Dr Emily Castell thank you for agreeing to supervise me over this journey. Lauren, Peta, and Emily, thank you for the unconditional support and kindness you have shown to me, your unwavering belief that I could finish, and the many laughs throughout the years. I cherish the relationships we have formed and look forward to seeing how they will grow in the future.

To Professor Christobel Saunders, thank you for your guidance and feedback, particularly in the formative stages of the project.

To Bruce and Renae, thank you for being listening ears and shoulders (or armchairs) to cry on. Even when my rants were going in circles and I felt like giving up, you helped me to keep running the research marathon.

To my family, thank you for resisting the urge to ask when I would finish studying (most of the time). Thank you also for the love and support you have provided during this research project and throughout my life. As a side note, if you are reading this, I have finished studying now.

I would like to acknowledge the School of Psychology at Curtin University for providing the opportunity to conduct this research project, The Curtin University librarians for sharing their vast knowledge on data searching and, the contribution of an Australian Government Research Training Program Scholarship in supporting this research.

List of Included Publications

Chapter 3:

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2018). A systematic review of women's knowledge of screening mammography. *The Breast, 42,* 81-93. https://https://doi.org/10.1016/j.breast.2018.08.102

Chapter 4:

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2020). Subject positions in screening mammography and implications for informed choice. *Psychology & Health,* 1–18. Advance online publication. https://https://doi.org/10.1080/08870446.2020.1766043

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Statements of Contributors

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2018). A systematic review of women's knowledge of screening mammography. *The Breast*, *42*, 81-93. https://https://doi.org/10.1016/j.breast.2018.08.102

The purpose of this statement is to detail the nature and extent of the intellectual contribution by the PhD Candidate, Kristen Seaman, and all other co-authors of this study publication. Associate Professor Lauren Breen, Dr Peta Dzidic, and Dr Emily Castell were involved in the overall supervision of the PhD, supporting the conception and design of the study, interpretation of results, and writing of the manuscript. Professor Christobel Saunders supported the writing of key sections of the manuscript, and overall feedback. Kristen Seaman contributed to the conception and design of the study, and led the data collection, analysis, and interpretation, and manuscript writing.

I affirm the details stated in the Statement of Contribution are true and correct.

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Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2020). Subject positions in screening mammography and implications for informed choice. *Psychology & Health*, 1–18. Advance online publication. https://https://doi.org/10.1080/08870446.2020.1766043

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Dr Peta Dzidic	

List of Conference Presentations

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2019, May 15). *A systematic review of women's knowledge of screening mammography*. Paper presented at the Behavioural Research in Cancer Control Conference, Perth, Australia.

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2019, March 27). *The social construction of screening mammography: Implications for informed choice and communication.* Paper presentation at the Mark Liveris Health Sciences Research Student Seminar, Perth, Australia.

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2018, June 1). *The Illusion of choice: Women's constructions of participations and non-participants in screening mammography.* Paper presented at the Critical Health Education Studies Conference in Queenstown, New Zealand.

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2017, November 14). *The social construction of mammography: Implications for informed consent, autonomy and communication.* PhD Candidacy Proposal presented at the Dennis Glencross Conference, Curtin University.

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List of Abbreviations

AIHW	Australian Institute of Health and Welfare
DCIS	Ductal carcinoma in situ
FDA	Foucauldian discourse analysis
GP	General practitioner
ICSN	International Cancer Screening Network
NCI	National Cancer Institute
NIH	National Institute of Health
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analysis
RACGP	Royal Australian College of General practitioners

Appendices

Chapter 1: Introduction

1.1 Chapter Overview

In Chapter 1, I provide a review of breast cancer and screening mammography, in relation to cisgender women, both broadly and within Australia, before highlighting the contested evidence surrounding the practice in terms of the benefits and harms posed to asymptomatic women. I then present a rationale for the importance of supporting women in making an informed decision by drawing attention to the appropriateness of framing screening as an individual enterprise, rather than that of a public health intervention. However, in an endeavour to support informed decision-making, I do not adopt the dominant framework of autonomy within the medical field (a biomedical perspective), and instead introduce a feminist-informed framework. Aligning with my feminist-informed perspective, I then summarise relevant socio-cultural, historical, and political factors/processes that arguably shape women's experiences within the breast screening context. I conclude the chapter by drawing on the reviewed research to present a strong rationale for my project, introduce key terms, articulate my position as the researcher, and present the project objectives and thesis structure.

1.2 Breast Cancer

Breast cancer is the abnormal growth of cells in breast tissue. Cells grow abnormally in the breast lobules, which produce breast milk, or ducts, which carry milk to the nipple (Cancer Council, 2018). When the cells grow uncontrollably, they have the potential to spread to surrounding breast tissue, and then to other body parts through the lymphatic system (Cancer Council, 2018). There are several types of breast cancer including non-invasive breast cancer, also known as ductal carcinoma in situ (DCIS), in which abnormal cells remain within the breast ducts; invasive breast cancer, in which abnormal cells have spread from the lobules or ducts to surrounding breast tissue or the lymphatic system; and other less common types such as locally advanced breast cancer, inflammatory breast cancer, and Paget's disease of the nipple (Cancer Council, 2018). The most common type of breast cancer is a type of early breast cancer called invasive ductal carcinoma, which accounts for 80% of breast cancer diagnoses (Australian Institute of Health and Welfare [AIHW], 2017). Invasive lobular carcinoma, another form of early breast cancer, accounts for 10% of breast cancers (AIHW, 2017). Overall, breast cancer accounts for 28% of cisgender women's cancers in Australia (excluding basal and squamous cell carcinoma of the skin) and is the most commonly diagnosed cancer for Australia women (AIHW, 2019).

Several risk factors to developing breast cancer have been documented including personal, family history/genetic, reproductive, medical, environmental, and lifestyle factors (Cancer Australia, 2018). One personal risk factor is being biologically female; by her 85th birthday, an Australian woman has a one in eight chance of being diagnosed with breast cancer (AIHW, 2019). Breast cancer can still develop within cis-men; however, it is far less common, in that men with breast cancer make up less than one per cent of all diagnosed breast cancers in Australia (Cancer Council, 2018). Another personal risk factor is increasing age; 70% of diagnosed breast cancers occur in women aged 40-69 years and another 25% of cases are diagnosed in women 70 years of age or over (AIHW, 2017). This is because, as a person lives longer, it is more likely that cells in their body will mutate and develop into cancer (AIHW, 2017). Women from a higher socioeconomic status are also identified as having an increased risk of breast cancer (Akinyemiju et al., 2015). However, this is likely due to reproductive factors and environmental factors. Reproductive factors that increase the risk of developing breast cancer include being older at the birth of a first child, not having children, prolonged exposure to oestrogen, and later menopause (the average age in Australia is 51 years; Walker et al., 2011). Environmental factors may include access to screening services, which can detect cancer sooner. Evidence also suggests differing breast cancer incidence rates (i.e., Australian women develop breast cancer less than European women, but more than Asian women), and that women from urban areas have an increased risk compared to women living in rural areas (Cancer Australia, 2018). However, the acting mechanisms appear to be differences in lifestyle, reproductive, and environmental factors. A final personal risk factor is the positive relationship between higher breast density and risk of breast cancer (Pettersson et al., 2014).

Although most women diagnosed with breast cancer do not have a family history of breast cancer, research indicates that having a first-degree relative diagnosed with breast cancer can increase a woman’s risk (Cancer Australia, 2018). A woman’s risk is also increased by the inheritance of mutations on genes BRCA1, BRCA2, or CHEK2 (Cancer Australia, 2018). Medical risk factors include previous diagnoses of DCIS, or any other non-cancerous breast conditions, and long-term hormone replacement therapy (Cancer Council, 2018). Finally, lifestyle factors such as drinking alcohol, weight gain in post-menopausal women, and limited physical activity have been identified as increasing risk (Pandeya et al., 2015). As such, maintaining a healthy diet and weight, limiting alcohol consumption, and engaging in regular exercise have been identified as risk-reducing strategies, although it should be noted that there is no way to prevent the development of breast cancer (Cancer Australia, 2018).

Due to improved treatment, early detection methods, and a reduction in the use of hormonal replacement therapies by post-menopausal women, survival rates have increased over time (Atkin et al., 2008). For example, data from 2011-2015 indicated a 91% chance of surviving five years post-diagnosis, representing a significant improvement compared to the 72% five-year survival rate reported in 1982-1986 (AIHW, 2019). The survival figure has remained relatively stable in more recent years; data from 2007-2011 indicated a 90% chance of surviving five years post-diagnosis (AIHW, 2014). However, in light of improved treatment modalities, debate exists on the extent to which screening mammography currently contributes to survival rates and on the continued utility of screening in light of the advances in breast cancer management and treatment (Olver & Roder, 2017).

Treatment options for women diagnosed with breast cancer include surgery to remove some (lumpectomy) or all of the breast (mastectomy); chemotherapy to help shrink the cancer; radiation therapy, often used in conjunction with a lumpectomy, to destroy any undetected cancer; and hormone therapy to reduce levels of female hormones in the body that may be contributing to the growth of the cancer (Cancer Council, 2018). Despite improvements in treatment, health officials still recommend that women participate in practices that can detect cancer early (Cancer Australia, 2015). The 2015 position statement from Cancer Australia outlines that women should engage in breast awareness, wherein women should be familiar with the shape and feel of their breasts, and understand what is "normal" for them, and for women aged 50-74 years to engage in biennial screening mammography (Cancer Australia, 2015). Women aged 40-49 and above 75 years of age are encouraged to consider the potential benefits and harms of screening for their age groups, while women under 40 are not recommended to screen, unless personal circumstances exist (i.e., individualised screening regime due to categorisation as high risk; Cancer Australia, 2015).

1.3 Screening Mammography

Screening, as defined by the World Health Organization is "the presumptive identification of unrecognized disease in an apparently healthy, asymptomatic population by means of tests, examinations or other procedures that can be applied rapidly and easily to the target population" (https://www.who.int/cancer/prevention/diagnosis-screening/screening/en). As such, all cancer screening is based on the idea that early detection equates to a better prognosis and reductions in mortality and morbidity. From these ideas, treatment options, such as the surgical removal of the breast, became available. However, in the late 1800s and early 1900s, surgery often left women disfigured and with restricted use of their arm (Lowy, 2009 as cited in Parker, 2016).

In 1913, a surgeon from Berlin, Albert Salomon, was the first person to document attempts at diagnosing breast abnormalities using radiography (Gold et al., 1990). From here, the ability of X-rays to detect non-palpable lumps was realised, and enthusiasm for breast screening grew (Gold et al., 1990). Enthusiasm particularly grew from research that suggested the detection and treatment of breast cancer in early stages could lead to reductions in breast cancer-specific mortality and morbidity. I discuss such research later in this chapter when considering the efficacy, harms, and benefits of screening. Thus, breast screening refers to specialised medical imaging that uses X-rays to see inside the breast (BreastScreen Australia Evaluation Taskforce, 2009). In this research, when I discuss breast screening or screening mammography, unless specified otherwise, I am referring to digital mammography.

1.3.1 Screening Mammography in Australia

Although the national screening program did not commence until 1991, pockets of breast screening practices existed in Australia as early as the 1960s. For example, from 1961-1963, Marjorie Dalgarno, a radiologist from Sydney, conducted 1300 mammograms on asymptomatic women at the Rachel Forster Hospital in the gynaecological cancer detection clinic (Parker, 2016). Her practice contributed to the development of a standardised technique (Parker, 2016). In 1971, Medicheck, a Sydney-based clinic, screened nearly 12,000 asymptomatic women referred by their general practitioners (GPs) who deemed them at high risk of developing breast cancer (Croll et al., 1977). Following the release of key research papers supporting screening mammography (e.g., Tabar et al., 1985), the Australian Government initiated research into the cost and feasibility of a nationwide breast screening program in 1987 (BreastScreen Evaluation Taskforce, 2009). Movements towards the national screening program often coincided with the release of research that supported screening; however, the results of such research have been debated in recent times (Gøtzsche & Jørgensen, 2013; later reviewed in this chapter). The national screening program, BreastScreen Australia, began in 1991 and, although all women aged 40 and over were offered biennial screening, the program specifically recruited women aged 50-69 years old (Department of Health, 2018). In 2013, the program extended to actively recruit women 70-74 years of age (Department of Health, 2018).

Currently in Australia, free population-based breast screening is offered by BreastScreen Australia (AIHW, 2019), which offers digital mammograms to examine asymptomatic women's breasts for screening purposes (BreastScreen Australia Evaluation Taskforce, 2009). Women aged 40 and over are eligible for a free mammogram every two years; however, the program targets women aged 50-74 (AIHW, 2019). BreastScreen Australia aims to "reduce morbidity and mortality from breast cancer through an organised systematic approach to the early detection of breast cancer using screening mammography" (BreastScreen Australia Accreditation Review Committee, 2019, p. 20). The program operates throughout Australia, with over 600 locations nationwide (BreastScreen Australia Accreditation Review Committee, 2019). Each state follows national guidelines but the program is operated at a state or territory level and includes programs in the following areas—Australian Capital Territory, New South Wales, Northern Territory, Queensland, South Australia, Tasmania, Victoria, and Western Australia.

BreastScreen Australia invites women aged 50-74 to attend screening via an invitation letter first received approximately on their 50th birthday (BreastScreen Australia Evaluation

Taskforce, 2009). Invitations to re-screen are then sent every two years for women aged between 50-74 years and discontinued after the age of 74 years (BreastScreen Australia Evaluation Taskforce, 2009). Appointments can be made by phoning a local service or booking online. The appointment takes approximately 15 minutes and requires that a woman read and sign a participation consent form (BreastScreen WA, n.d). Each woman receives her results two to three weeks later via SMS or mail. In addition, women are requested to consent to and provide the contact details of a GP to whom they would like the results sent (Cancer Institute New South Wales, n.d). GPs are encouraged to place a re-screen reminder in their patient records to assist with encouraging eligible patients to participate in the program (Cancer Institute New South Wales, n.d). BreastScreen Australia's key performance indicator is participation rate (AIHW, 2019). The current national average is 54% and the BreastScreen Australia's National Accreditation Standards aims for a participation rate of 70% (AIHW, 2019).

1.3.2 The Efficacy, Harms and Benefits of Screening Mammography

To date, eight randomised controlled trials investigating the efficacy of screening mammography in mortality reduction have been conducted (Smith et al., 2004). Of these eight, three are considered to be adequately randomised—the Malmö trial, the Canadian trial, and UK Age trial (Gøtzsche & Jørgensen, 2013; Smith et al., 2004). Of the trials considered to be adequately randomised, none found a statistically significant effect in the relative risk reduction of breast cancer deaths and all-cause mortality 7 and 13 years later (Gøtzsche & Jørgensen, 2013). Furthermore, a 25-year follow-up of the Canadian Trial revealed that 171 women in the control group and 180 from the mammography group died of breast cancer (Miller et al., 2014). Such a small difference positions mammography as ineffective in reducing breast cancer mortality for women aged 40-59 years. Comparatively, the remaining trials, four of which are classified as sub-optimally randomised and the remainder considered too biased to provide reliable data, yielded favourable results towards mammography (Gøtzsche & Jørgensen, 2013). Specifically, it was the favourable results from the 1963 New York Trial and 1977 Two County Trial that shaped decisions to begin screening programs (Gøtzsche & Jørgensen, 2013).

The New York Trial, also known as the Health Insurance Plan trial, involved approximately 64,000 women aged 40-64 (Shapiro et al., 1985). Every 18 months, for four rounds, women randomly allocated to the clinical breast examination/screening mammography condition were invited to partake in a mammogram (Shapiro et al., 1985). A 10-year follow-up reported 30% fewer breast cancer deaths in the clinical breast examination/mammography group compared to the control (Shapiro et al., 1985). The 1977 Two Country Trial in Sweden reported similar results in that there was a 31% reduction in breast cancer deaths in the mammography condition compared to the control (Tabar et al., 1985). Each trial positioned mammography as a useful tool in reducing breast cancer mortality (Shapiro et al., 1985; Tabar et al., 1985). However, critics noted concerns for the comparability of groups in each study and potential bias through the conduct of non-blind death assessments. They concluded by questioning the recommendation of screening mammography to any age group (Gøtzsche & Jørgensen, 2013).

A meta-analysis of the eight randomised control trials estimated a 15-20% reduction in the relative risk of breast cancer-specific mortality (Pace & Keating, 2014). Assuming this figure is 15%, over a 10-year period, 1 in every 2000 women will avoid dying through detection of breast cancer via mammography (Gøtzsche & Jørgensen, 2013). Arguably this demonstrates benefit; however, contention surrounds the benefit-risk ratio in that, of those 2000 women, 10 healthy women will be overdiagnosed and treated unnecessarily and 200 will experience psychological distress incurred from receiving false-positive results (Gøtzsche & Jørgensen, 2013).

The most concerning potential harm arising from screening mammography is the risk of overdiagnosis, which is the detection of a tumour which would not otherwise become clinically evident in the patient's lifetime, had screening not occurred (Pace & Keating, 2014). Currently, it is not possible to distinguish between fatal and harmless cancers; thus unnecessary treatment is unavoidable (Jørgensen & Gøtzsche, 2009). Systematic reviews investigating the incidence of overdiagnosis in breast cancer report figures ranging from 19% to 52% (Bleyer & Welch, 2012; Independent UK Panel on Breast Cancer Screening, 2012; Jørgensen & Gøtzsche, 2009). Researchers often conclude that one in three breast cancers is overdiagnosed (Bleyer & Welch, 2012; Jørgensen & Gøtzsche, 2009). Overdiagnosed cancers contribute to the ambiguity in assessing survival benefits from screening due to length time bias, which is the tendency of screening to detect slow growing cancers, which naturally have a better prognosis, over fast growing, more lethal cancers. This bias denotes screen-detected cancers lead to longer survival time, even if no real benefit from detecting the cancer via the screen was experienced (Duffy et al., 2008). Higher figures, such as the 52% reported in Jørgensen and Gøtzsche (2009) meta-analysis, may be attributed to the inclusion of DCIS, which is a non-invasive breast cancer that poses no threat to life unless it develops into invasive breast cancer (Jørgensen & Gøtzsche, 2009). Research suggests 20-30% of women who do not seek treatment will develop invasive breast cancer (Jørgensen & Gøtzsche, 2009). Currently, it is not possible to predict which DCIS will develop into invasive breast cancer. When DCIS was excluded, the percentage of overdiagnosis decreased to 35% (Jørgensen & Gøtzsche, 2009).

Further harms of mammography may arise from false-positives. A woman may be re-called for further tests when she does not have breast cancer (AIHW, 2018). BreastScreen reports that 10% of first-time attenders, and 3% of returning attendees, will experience a false positive (AIHW, 2018). Consequences of false-positive results include increased anxiety, breast-cancer specific anxiety, and perceived risk of breast cancer. (Nelson et al., 2016; Salz et al., 2010; Tosteson et al., 2014). Authors of a recent systematic review reported evidence for both persistent and transient anxiety arising from false positives (Nelson et al., 2016) .

Persistent anxiety is supported by longitudinal studies (e.g., Aro et al., 2000) examining psychological distress across three groups of women—those receiving normal mammography results, false-positives, and outside referents (i.e., those engaging in opportunistic screening as opposed to the screening within the national screening program)—2 and 12 months post-mammography. The study was further strengthened by adjusting for background factors, personality, and pre-screening distress. At both 2 and 12 months, the false-positive group experienced greater intrusive thoughts and worry about breast cancer and engaged more frequently in breast self-examination (Aro et al., 2000). Considering evidence that breast self-examination does not reduce breast cancer specific mortality (McCready et al., 2005), performance of the practice may serve to create false states of security. Women in the false-positive group also perceived a heightened sense of breast cancer risk, although they did not experience increased general health worry (Aro et al., 2000). A systematic review of controlled and qualitative studies conducted in the United Kingdom reported an increase in breast cancer-specific anxiety for up to three years following the receipt of a false-positive result (Bond et al., 2012).

However, other studies have shown that the anxiety experienced by women following a false-positive is short-lived (Ekeberg et al., 2001; Gilbert et al., 1998; Tosteson et al., 2014). On the day of re-call, women experienced borderline to clinically significant levels of anxiety and depression (Ekeberg et al., 2001; Gilbert et al., 1998). At a four-week (Ekeberg et al., 2001), five-week and four-month (Gilbert et al., 1998) follow-up from the final diagnosis, anxiety and depression scores had significantly decreased. A more recent study noted significantly higher anxiety scores for women receiving a false-positive compared to those receiving a normal result; however, there was no difference between groups one year later (Tosteson et al., 2014). Each study provides support for transient anxiety following a false-positive result but it should be noted that each study used measures of general anxiety and depression (Ekeberg et al., 2001; Gilbert et al., 1998; Tosteson et al., 2014) whereas the research supporting long-term anxiety effects relates to breast cancer-specific anxiety only (Nelson et al., 2016; Salz et al., 2010).

Other reported harms of mammography include pain during the mammogram (Nelson et al., 2016). The brochure provided by BreastScreen Australia, “BreastScreen and You,” informs women that a mammogram may cause discomfort (Cancer Australia, 2015). A systematic review of 22 studies investigating pain from mammography concluded the prevalence of pain varied widely, with 15% to 76% of women reporting pain (Armstrong et al., 2007) .

A final harm to consider is radiation (Nelson et al., 2016). The ‘BreastScreen and You’ brochure states that women’s breasts will be exposed to a small amount of radiation, approximately the same amount occurring from 18 weeks’ exposure to the environment (Cancer Australia, 2015). To date, no study directly examines the relationship between mammography radiation and breast cancer incidence and death (Nelson et al., 2016). However, a modelling study suggests, for women screened annually from the age of 40-55, then biennially thereafter to age 74, radiation will induce 86 cancers and 11 deaths per 100,000 women (Yaffe & Mainprize, 2011).

Benefits of screening may include the detection of smaller/asymptomatic cancers (i.e., DCIS cancers), that, when compared to the detection of larger/symptomatic cancers, can lead to increased treatment options, survival chances, and breast-conserving surgery (AIHW, 2019). In addition, the detection of smaller/asymptomatic cancers provides a decreased risk for hormone therapy and adjuvant chemotherapy when compared to the detection of larger/symptomatic cancers (Armstrong et al., 2007). Further benefits include reassurance; in qualitative interviews, women reported feeling reassured post-mammography after a receiving news that there is no cancer. (Griffiths et al., 2010). Finally, the reduction in relative risk of breast cancer-specific mortality is often cited as 15-20% (Myers et al., 201; Pace & Keating, 2014) but this benefit varies across age group. For example, Myers et al.'s (2015) systematic review examined 43 studies assessing the contribution of mammography to breast cancer mortality. They noted that screening women aged 40-49 led to a 15% reduction in breast cancer mortality, while screening women aged 50 and over led to a 14-23% reduction in mortality. However, this greater reduction was related to the reduction reported in women 60-69 years of age (31%; Myers et al., 2016). A similar benefit can be roughly quantified as, for women aged 39-49, 1904 women need to be invited to have mammography in order to prevent one breast cancer death compared to 377 women aged 60-69 (Nelson et al., 2016). The literature acknowledges the evidence for reductions in breast cancer-specific mortality for women aged 40-49 is limited, whilst women 70 and older may begin to experience more harm than benefit from mammograms (Mathieu et al., 2007, 2010).

1.3.3 Informed Decision-Making: An Ethical Debate in Screening Mammography

In considering the ethics of screening mammography, experts have questioned if national screening mammography programs should be understood as an individual enterprise, in which participation serves to only benefit the individual, or as a collective enterprise, where participation is a public service that benefits the population (Juth & Munthe, 2012; Verweij, 2000). As noted by Parker and Carter (2016), this questioning is important as it guides which ethical framework best underpins such programs. Common approaches include biomedical ethics, which broadly assert that individuals should benefit from participation, that unnecessary harm should be avoided, that all should have equal opportunity to participate, and that autonomous decision-making should be supported (Beauchamp & Childress, 2001). Another common approach is public health ethics which includes, but is not limited to, the delivery of more benefits than harms, maintenance of transparency, even distribution of benefits and burdens, upholding reciprocal obligations and acting in solidarity with others, and ensuring privacy and confidentiality, accountability, and trust (Abbasi et al., 2018). Of greatest interest to my research is the extent to which informed decision-making is supported within each of these frameworks. An informed decision, for the purpose of this research, is understood as providing full and accurate information on the benefits and harms of participating, and not participating, and that a decision is made without undue influence from others (Plough et al., 2012).

Those adopting a public health ethics framework may not prioritise informed decision-making for several reasons. For example, they might view the facilitation of an informed decision as a time-consuming process that impedes other clinical care (Entwistle et al., 2008). Others suggest that it may be burdensome and unreasonable to expect patients to make an informed decision in the context of ongoing debates concerning benefits and harms (DuBenske et al., 2017; Siedlikowski et al., 2018). Further to this, some health experts express a concern that, due to the complexity of communicating harms such as overdiagnosis, that information may be misrepresented to the public and lead to a reduction in participation rates (Entwistle, 2004; Parker et al., 2015a). These concerns can lead health experts to propose solutions that ultimately limit women’s capacity to make an informed decision—keeping discussions about overdiagnosis confined to academic circles and only discussing overdiagnosis with women at the point of mammography or upon diagnosis (Parker et al., 2015a). For those adopting a public health perspective, keen attention is given to achieving high participation rates, which is a key performance indictor of national screening programs (Cancer Australia, 2020), and argued by some to be necessary to ensure that screening benefits (e.g., ongoing reductions in mortality due to the program's ongoing implementation sustainability), are realised (Weller & Campbell, 2009).

However, many of these concerns are questionable. For example, the assumption that making an informed decision is burdensome might not hold true for all women; research consistently highlights the variability within women's preference for shared decision-making in the context of screening mammography, with most studies noting that at least half to most of their sample prefer shared decision-making (Chamot et al., 2004; Davey et al., 2002; Hoffman et al., 2010). The assumption that informed decision-making is too complex for women, thus is an unreasonable expectation, is also ill-founded. For example, with tools such as decision aids, complex information can be delivered in consumer-friendly formats. Decision aids are broadly defined as interventions that assist people in making decisions between various courses of action (Entwistle, 2000). Research demonstrates that decision aids aimed at enhancing women's knowledge about screening mammography have led to an increase in informed decision-making (Hersch et al., 2015; Mathieu et al., 2007, 2010). Further, I argue the assumption that informed decision-making is unreasonable in the face of complexity is particularly problematic as it positions informed choice as a bounded practice afforded to only those deemed "educated enough," which reinforces medical hegemony and promotes paternalistic practice. Finally, the concern that supporting women to make an informed choice will lead to a decline in participation is a contentious claim—systematic reviews report uncertainty as to whether informed decision-making in screening (including prostate, antenatal, screening mammography) affects participation rates (Edwards et al., 2003; Jepson et al., 2001). Other studies examining the impact of decisions-aids on informed decision making for screening mammography reported no change to participation rates

(Mathieu et al., 2007; Pérez-Lacasta1 et al., 2019) while others reported reductions in participation for women, particularly those aged 38-50 years (Ivlev et al., 2017), and reductions in women's intentions to screen (Hersch et al., 2015).

Nonetheless, the application of public health ethics, and associated practices, to national screening mammography programs could still be argued as appropriate—albeit through debatably weak points. For example, a key component of public health interventions is that they serve *all* of the public's interest (Verweij, 2000). If the reductions in mortality associated with screening mammography are considered as serving the interest of the public (for example, in part by reducing mortality) then screening mammography programs reflect this public characteristic (Parker & Carter, 2016). Further to this, some note that screening programs act more like social institutions rather than isolated patient-provider interactions, and as such have a degree of publicness about them (Parker & Carter, 2016). Unlike isolated patient-provider interactions, public health interventions are governed by specific internal regulations and have particular functions and goals (Juth & Munthe, 2012). Such characteristics can be seen in BreastScreen Australia; for example, the program is characterised by specific regulations, that are enacted at both federal and state levels, and includes several goals—the program has a 70% participation rate for its target population (Cancer Australia, 2020), and serves to reduce mortality and morbidity associated with breast cancer and maximise early detection for women aged 50-74 years (BreastScreen Evaluation Taskforce, 2009). Finally, the national screening mammography program meets two criteria specified by Verweij and Dawson, (2007) that arguably characterises public health interventions—there is an aim to improve the health of the public and it is operated as a government funded intervention.

Overall, arguments that characterise the national screening mammography program as a public health intervention, thus justifiably apply associated public health ethics, are weak.

For example, I question if such programs truly serve the public's best interest considering that the benefits derived from a reduction in breast-cancer specific mortality associated with screening (e.g., that women may live longer and continue to benefit others economically and psychosocially) are at least partially offset by the morbidity associated with overdiagnosis, over-treatment, and lead-time bias (Ward, 1999). However, the notion that the screening program is in the public's best interest because it ensures women can continue to benefit others is, concerning. It suggests a woman's worth is her ability to contribute to others and neglects her intrinsic value (Parker & Carter, 2016). Others draw on ideas from Verweij (2000) who suggests public interest in programs dissipates if the program is compared to other, less contentious health interventions (Parker & Carter, 2016). For example, maintaining a healthy weight and diet are regarded as risk-reducing behaviours for breast cancer, and most other non-communicable diseases (Cancer Australia, 2018). Perhaps a public health intervention, such as universal access to nutritionally balanced food, would be of greater interest to, and of more use, to the public in reducing breast cancer mortality and morbidity than screening mammography programs. Thus, the assertion that a program has public interest, when compared to nothing else, is weak.

Furthermore, those supporting the characterisation of screening mammography programs as public health interventions highlight that, women themselves, have a public interest in national screening programs as evidenced by their dissatisfaction and/or suspicion towards changes in guidelines when less screening is recommended (Allen et al., 2013) and characterisation of screening as a moral obligation to others (Seaman, Dzidic, Breen et al., 2018; Willis, 2004). However, I argue that women participating out of obligation to others can be problematic for several reasons. First, participation in screening mammography does not offer a collective benefit like other public health interventions (e.g., vaccinations against infectious diseases). Second, there is no clear evidence that participation in screening mammography ensures services are kept cost-effective, thus open for other women (Parker & Carter, 2016). However, as noted by Parker and Carter (2016), this may differ for rural or community settings where minimum thresholds are needed to warrant service provision. Finally, participation arising from an obligation to others reinforces gender norms wherein women are positioned to put others before themselves (Gilligan, 1982/2009). This obligation precludes opportunities for women to act in the interest of the self and may contribute to the labelling of women who choose to not attend cancer screening (i.e., breast/cervical) as irresponsible women (Griffiths et al., 2010; Seaman, Dzidic, Breen et al., 2018; Todorova et al., 2006). Considering that screening mammography programs actively target asymptomatic women in attempts to alter the risk for a population, yet it is the individual woman who is more likely to bear the harms than reap the benefits, informed decision-making must be prioritised and supported in adopted ethical frameworks.

1.4 Key Ethical Perspectives in the Research

In this section, I locate breast screening within the dominant medical model of ethics, principlism, before refining the discussion to the principle of autonomy, and practice of informed consent. I dedicate considerable space to the principle of autonomy and the associated practice of informed consent due to the debates surrounding screening mammography presented in this chapter—an uncertainty in the balance of benefit and harm and reality that the individual participating rarely reaps the benefits of breast screening yet bears the harms. As such, I align with researchers who advocate for an examination of informed decision-making in the breast screening context (Entwistle, 2008; Lay & Jaye, 2009).

When discussing informed consent, I incorporate literature on women’s knowledge of screening, and on the communication of screening from media and health professionals, to examine current constraining and facilitating factors for informed screening decisions. I conclude by adopting a feminist ethics perspective to critique the biomedical perspective of autonomy and widen the conceptualisation of autonomy. From a feminist ethics perspective, I then consider new avenues in which opportunities could be made to support an informed decision in the breast screening context.

1.4.1 A Bioethical Perspective

The ethics of medical practice is informed by principlism, an applied ethical approach that denotes the importance of four key principles—beneficence, non-maleficence, justice, and autonomy (Beauchamp & Childress, 2001). Beauchamp and Childress (2001) assert that these principles are universal and as such are “applicable to all persons in all places, and we rightly judge all human conduct by its standards” (p. 3).

The principle of non-maleficence refers to the duty to do no harm; to not impose careless or unreasonable risk on to another (Beauchamp & Childress, 2001). However, harm, which could be regarded as justifiable, is permitted (Beauchamp & Childress, 2001). For example, killing is considered wrong but killing as part of self-defence may be justifiable. This tension plays out in the breast screening context when advocates for screening allow the potential for healthy individuals to incur harms for the benefit of others (e.g., to reduce mortality rates and maintain program accessibility/funding).

Beneficence asserts the duty that we act in the benefit of others; to assist them furthering their legitimate interests/values (Beauchamp & Childress, 2001). Beneficence differs from non-maleficence in that beneficence requires an active participation to better others, as opposed to harm reduction, which may be achieved by refraining from action (Iserson, 1999). In the breast screening context, the goal of the program, to reduce mortality and morbidity associated with breast cancer, represents an attempt at beneficence.

The principle of justice is concerned with how benefits and burdens are distributed throughout the population (Beauchamp & Childress, 2001). This principle is reflected in healthcare settings that strive to give assistance/resources to those in greatest of need. However, due to often scarce resources, selection systems such as waitlists or selection criteria may be employed (Iserson, 1999). In the breast screening context, women aged 50-74 are identified as experiencing the greatest need, thus are actively invited to screening, although women 40-49 and above 75 are still eligible for free screening at their own request.

Autonomy refers to “self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” (Beauchamp & Childress, 2001 p. 58). This definition includes core aspects of agency and liberty. Agency considers the individual’s ability to self-govern and asserts that an individual must possess competent decision-making capacity (Lau & Jaye, 2009). Competence is often bound within a person’s developmental age, mental, and physical health, and as such, can exclude people from autonomous decision making (Dodds, 2000). Liberty asserts that an individual’s decision is not controlled by others. According to Beauchamp and Childress (2001) control can arise from coercion, persuasion, and/or manipulation. Coercion renders a decision as non-autonomous by the direct threat, force, or control of another (Beauchamp & Childress, 2001). Persuasion characterises instances when an individual makes a decision based on the reasons/logic provided by another (Beauchamp & Childress, 2001). Manipulation refers to instances when a person’s actions are directed by another, without using coercion or persuasion and may be in the form of misinformation (Beauchamp & Childress, 2001). Overall, an autonomous decision is one that is made free from the control of others (voluntarily), with all relevant information (informed), and from a person with capacity to self-govern (competence).

1.4.2 Informed Consent

Autonomy is respected and supported through the process of informed consent. Informed consent requires that an individual is seen as a competent decision-maker, is provided all relevant information, understands the information, and voluntarily consents to the practice/procedure (Beauchamp & Childress, 2001). It is often measured as one's ability to understand the benefits and consequences of participating and to express an intention that is aligned with their values (Hersch et al., 2011; Mathieu et al., 2010).

Research suggests that, in the breast screening context, a woman's decision to attend screening may not be an informed decision (Hersch et al., 2015; Seaman, Dzidic, Castell et al., 2018). Barriers identified include an inaccurate understanding of the benefits and harms of screening (Domenighetti et al., 2003; Gigerenzer et al., 2009; Schwartz et al., 2004), misinformation, as perpetuated by print and web-based media (Jørgensen & Gøtzsche, 2004; 2006), and inadequate support from health professionals in making informed breast screening decisions (Fowler et al., 2013; Gunn et al., 2015; Hoffman et al., 2010).

1.4.2.1 Women's knowledge of screening mammography

Literature suggests that most women overestimate the benefits of participating in screening mammography. For example, in studies examining women's perceptions of mammography in Switzerland, the UK, and Italy, researchers noted that 50-70% of women overestimated the benefit to mortality (Chamot & Perneger, 2001; Domenighetti et al., 2003). In another study, women from France, Germany, and the Netherlands overestimated the benefit to mortality by a factor of 10 or more or did not know the benefit (Gigerenzer et al., 2009). The extent to which early detection contributed to survival was also overestimated in women from Spain; 94.1% agreed that breast cancer could be cured if detected early via screening mammography (Luengo-Matos et al., 2006). Overestimates of the benefits afforded to women outside of targeted age ranges were also reported; 38% stated screening had "proven" benefit for women aged under 40, 83% reported screening had "proven" benefit for women 40-49, while 41% of 360 women surveyed characterised an 80 year old woman as irresponsible for ceasing breast screening (Schwartz et al., 2004).

There is also evidence that some women experience confusion regarding the purpose of screening. For example, a study conducted by Blue Moon Research and the Australian Government's Department of Health and Ageing (2008), via 19 focus groups with women aged 40-80, suggested that most women felt screening mammography could be used as a diagnostic tool if a breast abnormality was self-detected. Confusion was also reported by English women surveyed in Webster and Austoker's (2006) research, with 45% of a sample of 1000 women reporting that the purpose of screening was to prevent cancer.

Conversely, women tend to be unaware or underestimate the potential for harm from participating in screening mammography. Specifically, several studies have reported that women have minimal awareness of the potential for overdiagnosis and/or are confused when information on overdiagnosis is presented (Hersch, Jansen, et al., 2014; Waller et al., 2013). Research conducted by Blue Moon Research and the Australian Government's Department of Health and Ageing (2008) reported that none of their participants were aware of overdiagnosis or the associated potential for overtreatment with screening mammography. More broadly, Schwartz et al. (2004) reported that 8% of women were unaware that screening could harm healthy women, while more specifically, Blue Moon Research and the Australian Government's Department of Health and Ageing (2008), concluded that many women who "regularly" (attend biennially) participate in BreastScreen Australia were unable to identify any associated harms. However, those categorised in lapsed/never groups (attended in the past, and not-attended in the recommended screening interval of 2 years) were more likely to cite harms. The most commonly-cited harms were the potential harm from radiation exposure, trauma to the breast via the mammography machine, and anxiety experienced by false positives. The potential for anxiety was accepted by some in this research as a “necessary evil” (Moon Research and the Australian Government’s Department of Health and Ageing, 2008, p. 82).

Tools such as decisions aids are being developed and used to enhance women’s knowledge of screening mammography. According to a Cochrane systematic review that aimed to assess the impacts of decision aids for people engaging in treatment or screening decisions, decision aids significantly increased patient’s knowledge, reduced decision conflict related to feeling uninformed, and decreased the amount of people feeling passive in their decision-making (Stacey et al., 2017). Similar results are reported with regards to decision aids aimed at enhancing women’s knowledge and increasing the percentage of women making an informed decision-making in the breast screening context (Hersch et al., 2015; Mathieu et al., 2010; Mathieu et al., 2007; Pérez-Lacasta et al., 2019). For example, several randomised control trials developed decision aids for women in their forties and reported an increase in women’s knowledge about screening mammography compared to control groups (Hersch et al., 2015; Mathieu et al., 2010; Pérez-Lacasta et al., 2019). Further to this, the number of women making an informed choice in intervention groups was significantly more than women in control groups; 23.2-24% of women in intervention groups made an informed choice, compared to 0.5-15% of women in the control groups (Hersch et al., 2015; Pérez-Lacasta et al., 2019). An informed choice in both studies was defined as adequate knowledge and consistency between screening attitudes and intentions. Another randomised control trial, this time assessing the impact of a decision aid aimed at women aged 70 years and over, also produced similar results (Mathieu et al., 2007). Women who received the decision aid significantly increased their knowledge scores compared to women in the control group and showed an increase in the percentage of women making an informed choice (73.5% vs

48.8%. $p < 0.001$; Mathieu et al., 2007). Concernedly, research on decision aids aimed at increasing women's knowledge of screening mammography and facilitating an informed choice for women within the target population (50-74 years old) appears limited.

1.4.2.2 Representation of screening mammography in the media

Mass media is considered a powerful source in shaping a/the populations understanding of health-related information (Atkin et al., 2008; Smith, et al., 2010; Walsh-Childers et al., 2011). The role of mass media is particularly important in the context of the national breast screening programs, which invites women to screen in the absence of a healthcare provider. Internationally, concern has been expressed that information provided to women via mass media persuades women to attend screening through misinformation, the ambiguous communication of screening, and framing mammography positively (Gigerenzer, 2014; Jones, 2004; Jørgensen & Gøtzsche, 2004, 2006; Schwartz, & Woloshin, 2002; Ward, 1999).

Misinformation can occur when mass media communications exclude information on the potential harms of screening, which has been documented by several studies. For example, a content analysis of invitations to screening mammography from seven countries, including Australia, found that mammography invitations omitted information concerning all-cause mortality or overdiagnosis, and that screening was framed positively overall (Jørgensen & Gøtzsche, 2006). In another example, an analysis of 27 breast cancer-related websites from Scandinavian and English-speaking counties created by government, advocacy, and consumer groups, found that that consumer-run websites provided balanced accounts of harm and benefit, while only four of the 24 government and advocacy-run websites mentioned overdiagnosis and over-treatment (Jørgensen & Gøtzsche, 2004).

Mass media also persuades women to screen via ambiguous communication of scientific research. For example, Schwartz and Woloshin (2002) examined how US print and television media presented changes in recommendations for women in their 40s, following announcements by the National Institute of Health (NIH) and the National Cancer Institute (NCI) in 1997. The NIH recommended against 1-2 year screening for women in their 40s and advocated for screening to be a women's decision. The uncertainty circulating in the scientific community surrounding this recommendation was reported in 67% of stories; however, 59% of the stories still suggested that women should probably or definitely screen. Only four stories highlighted screening as a decision to be made by women. The NCI later reversed the recommendation of the NIH and recommended 1-2 yearly screens for women 40-49. The uncertainty circulating in the scientific community surrounding this later recommendation was reported in only 21% of stories, while 96% of stories suggested women should screen (Schwartz & Woloshin, 2002).

However, it is important to note that some mass media content does attempt to communicate information accurately; Steele et al., (2005) examined how eight US newspapers presented information from scientific research, specifically the controversial research letter printed in The Lancet by Gøtzsche and Olsen (2001) that questioned the efficacy of screening in reducing mortality. Most of the articles in the media focused on people's reactions to the letter; however, some did attempt to provide information that would help women better understand the debate—why the trials were being debated, why people agreed and disagreed with the letter, methods used in analysis, and how to accurately interpret the numbers (Steele et al., 2005).

Finally, mass media has the potential to persuade women to screen by framing screening mammography positively. For example, in an analysis of media from BreastScreen Australia, it was reported that the messages in their material suggest that early detection saves lives, a doctor’s referral is not needed, mammograms can detect cancer the size of a grain of rice, breast cancer incidence is high, and that breast screening is the “best protection” (Blue Moon Research & Planning for the Australian Government Department of Health and Ageing, 2008; Jones, 2004, Market Access Consulting & Research, 2005 as cited in BreastScreen Australia Evaluation Taskforce, 2009). Specifically, screening was framed as the “best protection” in the campaign launched in 2001 that featured Sara Henderson, a breast cancer survivor and well-known Australian author/property owner (Jones, 2004). Although this campaign is no longer actively promoted, women reported recalling the message “you bloody well should” (attend screening) several years later (Blue Moon Research & Australian Government’s Department of Health and Ageing, 2008).

More broadly, the positive framing of screening mammography has been reported in several studies including an analysis of American newspapers between 1989 and 1991, where Yanovitzky and Blitz (2000) concluded that 95% of the 3339 news stories identified were favourable to screening. In another study, 65 articles identified in Australian women’s magazines between 1995 and 1998 were dominated by the theme that early detection via screening is crucial for survival (Wilkes et al., 2001). Furthermore, Smith et al. (2010) examined US print media coverage of cancer screening over a four-month period. They reported that breast screening was covered more than any other health screen and identified two main messages, which were derived from recently published scientific research—the power/efficacy of screening mammography and the potential for new screening mammography technology. Finally, a content analysis of breast cancer news (Atkin et al., 2008) and screening messages (Jones, 2004) published in American and Australian newspapers, magazines, and on television, found limited coverage of scientifically-proven risk-reducing behaviours and frequent advertisement of screening programs, which framed screening mammography as the only breast health practice.

1.4.2.3 Shared-decision making practices in primary care settings

GPs have been identified by women as credible and important sources of health-related information (Hoffman et al., 2010). As such, their advice on screening mammography could potentially influence women's perceptions and decision-making (Hersch et al., 2017). Shared decision-making assists women to make an informed decision by helping them to understand the benefits and harms of screening, presenting alternate options (including to not screen), encouraging questions, and supporting women to make individual decisions which reflect their values (DuBenske et al., 2017; Hersch et al., 2017). Aside from being recognised as a core aspect of ethical practice for health professionals (Hersch et al., 2011), shared decision-making reportedly leads to better outcomes and healthcare experiences, less regret, and fewer hospitalisations, diagnostic tests, and elective procedures (Bertakis & Azari, 2011; Leng et al., 2017; Stacey et al., 2011). Furthermore, some regard shared decision-making as an important step in empowering women to be active decision-makers in their healthcare (Leng et al., 2017). This has been cited as a key reason for women to begin to influence the commissioning and provision of services (Leng et al., 2017).

Public support for shared decision-making in primary care settings varies. For example, in a population-based survey of 2765 Canadian adults, 96% of respondents preferred to be offered choices and asked their opinions (Levinson et al., 2005). However, 52% preferred to leave the final decision to their GP. Levinson et al. (2005) suggested that this is consistent with prior work that suggests patients prefer their GPs to take the lead in "problem solving," which often involves making diagnosis' and treatment decisions, but prefer to be involved in "decision-making," which requires choosing between alternative treatments; arguably like screening tests (Deber, 1994). Although a thorough review of sociodemographic factors that correlate with preferences for decision-making styles is beyond the scope of my research, it is important to note that research does highlight some key influencing factors. For example, relevant to this research—women reportedly prefer to take an active role in decision-making more than men (Levinson et al., 2005), while women over the age of 45 years, and those regarded as very unwell prefer to adopt more passive decision-making styles (Chamot et al., 2004; Levinson et al., 2005; Say et al., 2006).

In relation to screening mammography, research indicates approximately half of women sampled want to engage in shared decision-making with their GP (Chamot et al., 2004; Davey et al., 2005; Nekhlyudov et al., 2005). For example, telephone interviews with 106 Australian women aged 45-70 years indicated that 42% preferred an active role in decision-making (Davey et al., 2005), while results from a mail-based survey of 2216 Swiss women aged 50-69 years reported that 45% preferred to engage in shared decisions with their GP (Chamot et a., 2004). A mail-based survey with 96 American women aged 40-44 years echoed similar results—46% preferred to make the decisions to screen after considering their GPs opinion (Nekhlyudov et al., 2005). Chamot et al.'s (2005) mail-based survey to 2305 Swiss women aged 50-69 years highlights that whether or not women want shared decision-making may be more complex than a clear desire for or against; they reported that what women want to know about screening mammography varies considerably. For example, 14% of women wanted detailed information on all topics (personal risk of developing breast cancer, prevention in general, role, benefits and limits of screening, minor, and major problems associated with screening, why some women do not screen), while 36% of women did not want detailed information on any topic. Fifty eight percent of women wanted at least general information on all topics, however 6% of women did not want any information. Finally, 39% of women did not want detailed information on the limits of screening or potential harms, and 19% of women were not interested in knowing why some women declined screening. These results differed from focus groups run by DuBenske et al. (2017) wherein 10 women aged 40-49 years all reported wanting their GP to inform them of the logistics of screening mammography and prepare them for potential outcomes (especially false positives).

Despite support for shared decision-making, (i.e., by approximately half of all sampled women), it is concerning to note that it often does not occur in practice. For example, in a national sample of American adults over the age of 40, screening mammography was framed as a choice to only 54.4% (Fowler et al., 2013), while in another national sample of American women under 50 years, this figure was lower at 31% (Gunn et al., 2015). In another study, a survey of health care providers (physicians in primary care settings and house staff) revealed up to one third do not discuss the benefits and harms of screening mammography with women, while most reported deciding which disease screening tests to order their patients (i.e., mammography, prostate-specific antigen), independent of patient preferences (Dunn et al., 2001). This figure was slightly more promising in Fowler et al.'s (2013) study, with only 39.6% of women not being asked about their preferences. In a national random digit-dial telephone survey of American adults aged 50 years and over, the majority reported that their health care provider was the one to most often initiate a discussion on screening (prostate, colorectal, and breast); however, their healthcare provider did not ask their preferences (Hoffman et al., 2010). More specifically, regarding discussions on breast screening, 49.9% of women reported that their health care provider discussed the benefits of screening “a lot”, but only 19.5% reported their health care provider discussed the harms (Hoffman et al., 2010). Despite most women reportedly feeling informed about screening mammography/breast cancer, most women overestimated their risk of being diagnosed with and dying from breast cancer, and few correctly estimated the predictive value of an abnormal mammogram (Hoffman et al., 2010). Together these results suggest that shared decision-making is either not regularly occurring, or when it is occurring, it perpetuates positive narratives about screening mammography, and/or fails to accurately convey all relevant evidence-based information (i.e., both benefits and harms).

Although shared decision-making practices are likely not facilitating an informed decision, in some studies most participants felt satisfied with their level of involvement in the process—Nekhlyudov et al. (2008) and Hoffman et al. (2010) conclude that although information exchange and involvement in decision-making was limited during the clinical encounter, most women felt somewhat satisfied with the process of shared decision-making. However, it is important to recognise that other studies indicate women often feel ill-prepared for understanding screening mammography (DuBenske et al., 2017), left out of the decision-making process, and/or regard their actions as "following doctor's orders" (Allen et al., 2013, p. 6).

It is also important to consider the barriers that GPs experience when attempting to facilitate shared decision-making. For example, reviews of patient and physician reported barriers to shared decision-making noted that the process is hindered by authoritarian or dismissive clinicians (Joseph-Williams et al., 2014; Légaré et al., 2008), patients' fear that, through greater involvement they may be perceived as difficult, which may lead to reduced care (Joseph-Williams et al., 2014), patients' perceptions of power/knowledge imbalances (Joseph-Williams et al., 2014; Légaré et al., 2008) and, a lack of awareness by clinicians regarding the value of shared decision-making (Dunn et al., 2001; Leng et al., 2017). Further to this, some GPs recognised that their role within shared decision-making (i.e., information exchange and reassurance) for screening mammography may be less relevant compared to other screening tests (e.g., prostate) as the exam is conducted outside of primary care settings (Blue Moon Research & Planning for the Australian Government Department of Health and Ageing, 2008; Hersch et al., 2017).

One of the most commonly cited barriers, by both GPs and patients, is time constraints on the clinical encounter (DuBenske et al., 2017; Dunn et al., 2001; Joseph-Williams et al., 2014). For example, patients reported that the time allocated for consultations is insufficient for shared decision-making, and that clinicians seem too busy or hurried during consultations (Joseph-Williams et al., 2014), while GPs assume that shared decision-making in the breast screening context is particularly time-consuming due to the uncertainty inherent in the evidence base (Blue Moon Research & Planning for the Australian Government Department of Health and Ageing, 2008; Siedlikowski et al., 2018). In response to this uncertainty some clinicians report feeling unclear on how to accurately convey information to patients (Dunn et al., 2001; Griffiths et al., 2005), regard the guidelines themselves confusing (DuBenske et al., 2017; Siedlikowski et al., 2018), believe that, as women do not raise the topic of overdiagnosis with them, that mentioning would be counter-productive (Blue Moon Research & Planning for the Australian Government Department of Health and Ageing, 2008) or, believe that particular information would be inappropriate (e.g., information on overdiagnosis) for patients with low health literacy (DuBenske et al., 2017; Siedlikowski et al., 2018). There is reported concern that encouraging greater involvement in decision-making from lay people may exacerbate inequalities and discourage some women from engaging in screening mammography (Blue Moon Research & Planning for the Australian Government Department of Health and Ageing, 2008; Hersch et al., 2017). For example, Parker et al.’s (2015c) research on breast screening communication by Australian health experts (clinicians, program managers, policymakers, advocates and researchers) reported that some experts were concerned that more transparent communication could lead to reduced participation rates and therefore, lower the benefits to breast cancer mortality and morbidity gained from the national screening program.

Further to this, Parker et al.'s (2015c) research sought to examine how values influence health experts' reasoning, judgement, and communication of the Australian national screening program. They identified that health experts understand and prioritise ethical values differently. For example, those prioritising autonomy supported providing comprehensive information to women, while those prioritising delivering benefit, supported the provision of limited information to ensure women were not discouraged from attending (Parker et al., 2015c). In another study, Parker et al. (2015b) identified three ways in which health experts communicate screening: (a) be screened, (b) be screened and here's why, and (c) screening is available, please consider what is right for you. Approaches (a) and (b) involve guiding women towards screening and approaches (b) and (c) promote full disclosure of information. Again, Parker et al. (2015b) identified that experts who advocated for guidance were concerned about maximising participation. These health experts also believed that the benefits of screening outweigh the harms, with some not regarding overdiagnosis as a harm, but instead meant that the screening program was performing as intended; thus, reducing breast cancer mortality and morbidity. Experts who advocated for less guidance were worried about overdiagnosis and enthusiastic about enabling women to make their own healthcare choices (Parker et al., 2015b). Using the same data, Parker and Carter (2016) shifted their analysis to consider how socially embedded concepts influence how health experts talk about screening mammography. They identified that some health experts "appeared to see themselves as being personally involved in and morally bound by reciprocal transactions within their breast screening activities" (Parker & Carter, 2016, p. 7). In the example provided, the health expert felt that, due to their years of government-supported medical training, they had a duty to provide guidance and advice about breast screening to women, as opposed to positioning this responsibility onto patients. While differing ethical and epistemological values are not identified specifically as barriers to shared decision-making, Parker et al.’s (2015b, 2015c) and Parker and Carter’s (2016) work supports the idea that GPs practice is influenced by more than environmental barriers or scientific evidence alone.

1.4.2.4 Summary

In the medical field, policymakers and practitioners are obligated, by principlism, to support autonomous decision making. I have discussed several ways in which efforts have been made to do so—decision aids that aim to increase women’s knowledge (Hersch et al., 2015; Mathieu et al., 2007, 2010; Pérez-Lacasta et al., 2019), independent reviews of print and web media that highlight misinformation (Atkin et al., 2008; Jones, 2004; Jørgensen & Gøtzsche, 2004. 2006; Schwartz & Woloshin, 2002; Steele et al., 2005), and examinations of shared-decision making preferences and practices in primary health settings (Chamot et al., 2004; Davey et al., 2005; Fowler et al., 2013; Gunn et al., 2015; Hoffman et al., 2010; Joseph-Williams et al., 2014; Légaré et al., 2008; Nekhlyudov et al., 2005). I regard these efforts as significant and important steps in promoting autonomous decision-making in the breast screening context, however, argue they have thus far neglected the influence of the socio-cultural and historical environment on breast screening decision-making (Lau & Jaye, 2009). For example, although decision aids have been found to increase the number of women making an informed decision in the breast screening context (Hersch et al., 2015; Mathieu et al., 2007, 2010), they have been criticised for oversimplifying individuals as rational healthcare consumers (Stefanek, 2011; Vahabi & Gastaldo, 2003). Or, while some research has aimed to examine the influence of socio-cultural factors (i.e., ethics, values and some socially embedded concepts), on health experts’ breast screening communication (Parker et al., 2015b, 2015c; Parker & Carter 2016), this research neglects examination of the influence of wider socio-cultural trends in preventative health and gender on health experts’ communication. More pertinently, the implications are not directly considered in the context of opportunities for informed choice for women.

The neglect of wider socio-cultural trends stems from the conceptualisation of “controlling forces” in Beauchamp and Childress’ (2001) as acts of direct force (coercion), the use of logic (persuasion), and misinformation (manipulation). The conceptualisation of “controlling forces” is limited in scope and in need of expansion to better reflect the true context in which breast screening decisions are made—one in which individuals are inescapability influenced by interpersonal relationships and the wider socio-cultural, historical, and political environment (Entwistle et al., 2010).

1.4.3 A Feminist Perspective

A feminist ethics perspective seeks to challenge the biomedical framework of shared decision-making, however, also has capacity to compliment the framework. Therefore, in this section, I discuss a feminist ethics perspective by first drawing attention to a multitude of viewpoints within the field, and more importantly, the commonalities. I then provide a brief review on several feminist-inspired criticisms of autonomy before introducing and aligning myself with a feminist perspective of autonomy, termed relational autonomy. Finally, I conclude this section by highlighting how the adoption of a relational account of autonomy changed my understanding of informed consent and led me to examine and support a process conceptualised as informed choice.

In briefly highlighting the differences in feminist ethics perspectives, and to provide a foundation on which to critique autonomy, I draw on Dodd’s (2000) identification of three feminist ethics approaches—liberal feminism, radical feminism, and cultural feminism. Liberal feminism belongs to a branch that has sought to reduce differences between the sexes (Dodds, 2000). This approach stems from a recognition of how patriarchal society has used key aspects and experiences of women's bodies (i.e., the ability to bear children and breast feed; bodily changes associated with menstruation, pregnancy, and menopause) to exclude women from public/economic fields and label women as inferior (Lupton, 1994; Tong, 1997/2018). In this way, liberal feminism downplays sex differences in efforts to enhance the capacity for personal choice and autonomy (Dodds, 2000). A criticism of the approach lies in this "downplaying"; a feature of the approach which is underpinned by an assumption that that women's bodily experiences are optional, that participation within them may be chosen and rejected at will, and neglects to consider the real and inescapable impacts of female embodiment in decision-making (Tong, 1997/2018).

Radical feminism, which may be considered under the branch of power-focused feminist ethics, examines the role of cultural, political, economic, and social structures that maintain a patriarchal society (Tong, 1997/2018). In doing so, radical feminism attends to the effects of race, gender, class, and sexuality in power distributions and works towards an equitable society (Dodds, 2000; Tong, 1997/2018). Regarding choice, radical feminism asserts that the mere expression of choice does not equate to an expression of autonomy, because the choices available may serve to reinforce patriarchal domination (Dodds, 2000; Tong, 1997/2018). Radical feminism has been criticised for being value-laden; if a woman makes a choice which, according to radical feminism, reinforces dominant ideologies and power dynamics, that choice may be viewed negatively (Dodds, 2000; Stoljar, 2018).

Cultural feminism draws from care ethics feminists who have sought to identify key aspects of femininity and regard them as something unique, special, and powerful about women (Lupton, 1994; Gilligan, 2009/1982). Like radical feminism, cultural feminism asserts that choice/decision-making in the healthcare context is not an individual or isolated process (Dodds, 2000). However, cultural feminism privileges the value of relationships and their influences, rather than seeing them as potentially oppressive forces (Dodds, 2000). As such, cultural or care-focused feminism emphasises the evaluation of practice and policies on the basis of their capacity to foster or hinder relationships and on the assertion that relationships are central and valuable to people’s lives (Dodds, 2000; Gilligan, 2009/1982; Stoljar, 2018). However, some cultural feminist approaches have been criticised for potentially reinforcing the caring role of women, and positioning women into decisions that reaffirm women as subservient (Dodds, 2000; Stoljar, 2000).

There is no consensus on which approach to feminism is ‘correct’ (Stoljar, 2018; Tong, 2018/1997) and it is important to consider the factors that unite the perspectives. For example, feminist ethicists regard all people as full moral agents, acknowledge the cultural values associated with femininity (e.g., community, interdependence, relationships, care) and masculinity (e.g., independence, rules, status hierarchies), and value women’s moral experience/reasoning the same as men’s (Dodds, 2000; Donchin, 1995). Feminist ethicists are united by the endeavour to question women’s agency in a patriarchal society, their status as subordinate, and the factors that foster or ameliorate oppression (Dodds, 2000; Ells, 2003; Stoljar, 2018). Or, in the words of prominent feminist ethicists, Susan Sherwin (1996):

> Feminists share a recognition that women are oppressed in our society and an understanding that their oppression takes many different forms, compounded often by other forms of oppression based on features such as race, ethnicity, sexual orientation, and economic class. Because feminists believe that oppression is objectionable on both moral and political grounds, most are committed to transforming society in ways that will ensure the elimination of oppression in all its forms. (p. 48)

1.4.3.1 Feminist critique of autonomy

Feminist-ethics scholars often converge to criticise the notion of the liberal self that is privileged in biomedical definition of autonomy. The liberal self is abstracted from social, cultural, and historical relations, and entrenched with the idea that individuals make independent rational choices (Donchin, 1995; Stoljar, 2000). This type of individualism reinforces the false conceptualisation that individuals can exist outside of social relations and that at any time, individuals can voluntarily opt in and out of such social relations (Donchin, 1995; Stoljar, 2000). Such assumptions pose implications to women's capacity to engage in autonomous decision-making, reinforce individualist (i.e., masculine) qualities in society as normative, and negate consideration of oppressive structures and systems that may be limiting choice.

Feminists argue that autonomy privileges an independent sense of self; a quality that is associated with traditional notions of masculinity (Donchin, 1995; Meyers, 1989). As women are, from a post-structuralist positioning, socially constructed to value social relationships and interdependence, autonomy is inimical to women through its inherent devaluing of relationships (Stoljar, 2018). In this way, autonomy serves to disadvantage women in two ways—through the questioning of women's capacity to engage in autonomous decision making and through the reinforcement of masculine qualities as normative societal ideals. Research indicates that women's capacity to engage in autonomous decision making is at times questioned due to the perception that women are passive, emotional, and lack rational capacity (Dodds, 2000; Donchin, 1995). Such perceptions can perpetuate health inequalities, for example, some women are reported to experience increased paternalism in healthcare contexts, while other women have reported difficulty in accessing physical healthcare due to assumptions that their illness is emotionally, rather than physically caused (Dodds, 2000; Donchin, 1995).

If the core of autonomy lies in liberal rationality, women, whose capacity to engage in liberal rationality is at times questioned, may be systematically excluded from this practice. This exclusion then serves to further reinforce a masculine idea of autonomy as normative. Like feminists such as Gilligan (2009/1982), I reject a masculine sense of self as normative, and recognise the existence of gender differences in understanding the self, and in moral reasoning. Feminist ethics criticises autonomy for not considering, respecting, and supporting these differences (Dodds, 2000; Meyers, 1989). I argue that recognition of such differences is important because the elements that make the differences are always present. In this, I join feminists who reject the inherent claim in autonomy that suggests an individual can opt in and out of relational ties to make an autonomous decision. Instead, I and others argue that people are inescapably influenced by their socio-cultural, political, and historical environment (Donchin, 1995; Ells, 2003; Lau & Jaye, 2009). As such, the very nature of autonomy as an individual endeavour is flawed.

The idea that individuals are inescapably influenced by the socio-cultural world intensifies the need to critically consider how the social landscape may be influencing autonomy. Within feminist inquiry, there is a focus on identifying the potentially repressive influences of social instructions/practices (Dodds, 2000; Donchin, 1995). Although a biomedical understanding of autonomy does, to a narrow degree, critically consider how social landscape may influence autonomy, for example, Beauchamp and Childress (2001), draw attention to power imbalances between patients and health professionals; the focus on micro factors (i.e., personal dimensions/interactions) has been criticised for obscuring the influence of macro factors (i.e., social institutions and practices; Donchin, 1995).

In addition, it is important to note the difficulty identifying repressive social forces due to instances when oppression becomes internalised; instances when an individual may begin to unconsciously accommodate, and identify with the oppressive conditions (Stoljar, 2014). For example, some argue that this is reflected in women’s desires and practices to be thin; in this way a women’s desire to obtain a thin body appears as an exercise of autonomy and choice, however, such desire may be the result of internalising oppressive conditions that privilege the links between femininity, thinness, and beauty (Riley et al., 2018). In this way, there is a need to critically consider if the set of practices available from which to choose from, may in fact be collectively reproducing a singular “way of being” (Dodds, 2000; Riley et al., 2018).

Overall, feminists have critiqued the biomedical understanding of autonomy for the individualist, masculine, and voluntaristic biases inherent in the liberal self, and for negating an examination/consideration of how the social political, cultural, and historical environment influences autonomy (Dodds, 2000; Donchin, 1995). The criticisms presented in this section have contributed to feminist work in “rehabilitating” autonomy through the development of relational autonomy (Dodds, 2000; Meyers, 1989).

1.4.3.2 Relational autonomy

Feminist reconceptualisation(s) of autonomy are termed relational autonomy and include many variations. It is beyond the scope of this research to discuss the variations of relational feminism, and instead I focus on introducing a version that has informed my understanding of autonomy—procedural-based theories. Briefly, key features of procedural accounts include a recognition that individuals are influenced by the socio-cultural and historical world, an appreciation for decision-making in the context of relationships, a rejection of masculinity as normative and instead endeavour to support diversity in experiences, and the positioning of critical reflection as the benchmark for autonomous decision-making (Donchin, 1995; Stoljar, 2000).

Procedural based theories, and all relational theories of autonomy, reject the notion of the individualistic self, and argue that people are embedded within, and shaped by their socio-cultural and historical landscapes (Meyers, 1989; Stoljar, 2000). The term embedded also serves to recognise that such factors cannot be voluntarily opted in and out of, and instead are inescapably influential. As such, procedural accounts encourage critical consideration of the surrounding social institutions and practices which may influence an individual (Dodds, 2000). A refinement of Beauchamp and Childress' (2001) conceptualisation of autonomy also encouraged consideration of the impact of external forces in decision-making; however, such considerations have been criticised for being narrow in focus, and neglecting to analyse the impact of wider social institutions and practices (Ells, 2003; Sisti & Stramondo, 2015).

Like cultural feminists, procedural accounts do not de-value preferences which appear to reinforce normative and potentially oppressive forces. This is because procedural accounts are content-neutral, which allows for a multitude of different life plans to be regarded as equally “good” (Friedman, 2003; Meyers, 1989). In this way, autonomy is neither masculine nor feminine, and as such, it is distanced from a biomedical version of autonomy which constructs masculinity as normative. This perspective is preferable for my research as I refrain from evaluating screening participation as either “good” or “bad”, and by extension refrain from judging women's engagement, or non-engagement in screening, as acts of resistance or reinforcements of normative gender ideologies. In addition, by accepting all “life plans” equally, a foundation is created in which diversity is protected and encouraged (Friedman, 2003; Meyers, 1989).

A procedural conception stipulates that an autonomous decision is made “when an agent chooses or acts in accord with wants or desires that she has self-reflectively endorsed” (Friedman 2003, p. 5). The term self-reflectively endorsed may initially appear similar to ideas of self-sufficiency found in biomedical autonomy; however, in procedural approaches, autonomy is also compatible with dependence and connection (Stoljar, 2000). For example, Nedelsky (1989) emphasised that relationships, rather than isolation, are what enable people to be autonomous. Through relationships, such as with parents, friends, and teachers, the necessary guidance and support that enables the development and eventually experience of autonomy, is provided (Nedelsky, 1989). In drawing from this idea, Friedman (2003) noted that autonomy is developed by social relationships and engagement with multiple viewpoints.

Procedural theories regard people autonomous when they "exercise a repertoire of skills to engage in self-discovery, self-definition and self-direction" (Meyers 2005, p. 49). In procedural theories, an individual is required to critically self-reflect on their wants/desires and consider if their actions align with their authentic self (Friedman, 2003). While this appears similar to the biomedical measurement of informed consent (e.g., wherein there is a consideration of whether or not the individual's decision aligns with their values; Hersch et al., 2011; Mathieu et al., 2010), I argue that the biomedical "self-reflection" is superficial. This is because I align with Christman (1991) who considered an individual to be authentic if they were to critically reflect on the socio-cultural and historical processes that led to having a certain desire, and not then feel alienated from that desire. Alienation is experienced as a negative judgement or emotional reaction to the desire (Chrisman, 1991). As demonstrated in this chapter, through a lack of awareness about the benefits and harms of screening (Domenighetti et al., 2003; Gigerenzer et al., 2009), and favourable narratives perpetuated by mass media and health professionals about screening mammography (Atkin et al., 2008; Dunn et al., 2001; Hoffman et al., 2010; Smith, et al., 2010), it is likely that women are positioned to have a certain desire; to screen. It is clear then how the process of self-reflection, thus autonomy, may be facilitated by an exposure to multiple viewpoints, and an awareness of potentially powerful social institutions and embedded practices in forming that desire/want. By doing so, an opportunity is provided for procedural accounts of self-reflection.

I recognise that the process of self-reflection described here appears cognitively demanding, and to endorse hyper-rationality; however, I align with Friedman (2003) in noting that an individual's autonomous decision making, "need not be conscious" and that "autonomous choice…does not need to be highly deliberate or deliberated" (p. 8). Instead, "emotions and desires, as well as imagination, can constitute a kind of reflection on or attention to objects" (Friedman, 2003, p. 10). However, this perspective, one which encourages me to reflect deeply and critically is useful in my research. In addition, I argue that, based on the ethical obligations of policy makers and health professionals to support patients in making informed decisions that this perspective is also important for them to adopt. Before moving on to discuss a feminist-informed version of autonomy and informed consent, I draw attention to another key criticism of procedural theories—an inability to ascertain the effects of internalised oppression in forming desires/wants (Stoljar, 2018). Through recognition of this criticism, I hope to highlight potential experiences of internalised oppression in an endeavour to make available an additional perspective upon which women, health professionals, and policy makers *may* draw upon in relation to breast screening. However, I refrain from judging any women's choices/experiences as artefacts of internalised oppression, and firmly align with the notion that an autonomous decision is a product of an individual's critical self-reflection, which is actively supported within the environment.

1.4.3.3 Informed choice

Although the concept of informed consent is derived from a biomedical understanding of autonomy, in this research, I do not abandon the concept entirely. Instead, my research is informed by a practice termed informed choice which is rooted in the feminist relational approach to autonomy. Informed choice recognises that women are inescapably influenced by a range of socio-cultural, historical, and political factors, and pays keen attention to how social institutions attempt to discipline women based on race, sex, class, religion, or many other factors (Ells, 2003; Handa & Sharpe, 2015; Sherwin, 1992). Informed choice also recognises, and supports, the notion that women's decision making may be embedded in relational ties (Handa & Sharpe, 2015). In this way, there is a welcoming of other important people in a women's life during decision making, if she chooses. Through these recognitions informed choice aims to facilitate patients who are informed, autonomous, and participatory (Moulton & King, 2010).

During the process of informed choice, like informed consent, consideration is given to patient's values; however, informed choice extends past values and also considers an individual's social world, goals, and desires (Thachuk, 2007). Further differences between informed consent and informed choice pertain to the importance of knowledge—within informed choice opportunities for knowledge are privileged over the possession of knowledge as within informed consent (i.e., that individuals possess an accurate understanding of the benefits and harms of a procedure; Beauchamp & Childress, 2001). In addition, informed choice aims to support patients in either accepting or rejecting all options available (Handa & Sharpe, 2015). Specifically, rejections are more than "allowed" and instead respected as a valid choice (Handa & Sharpe, 2015). For example, this means that to choose to attend or not attend screening mammography within the national breast screening program for average "risk-women" are regarded equally as legitimate responses, or it could mean that a woman can request to not be provided educational tools about screening, yet still be regarded as making an informed decision.

Overall, it is clear that informed choice aligns with procedural theories of autonomy through the recognition of inescapable socio-cultural, historical, and political processes, the recognition and support of women to make decisions in relational contexts, the provision of opportunities for knowledge, and the recognition that acceptance or rejection of screening mammography invitations for average risk women are equally valid. As such, informed choice rejects the individualistic and voluntaristic bias inherent in biomedical versions of autonomy (and by extension informed consent) and works to displace traditionally masculine traits as normative and instead supports a diversity of experiences.

I align with researchers who are moving beyond informed consent in their research (Ells, 2003; Handa & Sharpe, 2015; Miner, 2017), and from this point in the thesis, explore the social construction of choice within screening mammography, and consider the implications of choice through a relational understanding of autonomy. As such, I use the words *autonomy* and/or *informed choice* to encompass the relational approach discussed in this section and the terms *biomedical-autonomy* and *informed consent* to represent the biomedical understanding of autonomy. However, it is important to note that the over the course of the thesis my conceptualisation of informed choice evolved, and that the definition provided in this chapter represents my most recent understanding. As such, studies conducted earlier in the research embody earlier understandings and language. For example, in Chapter 3 (a paper published in 2018), I use the term autonomy to represent biomedical-autonomy and advocate for the practice of informed consent. Further to this, in Chapters 3, 4, 5, and 6, a key component of my definition of informed choice is that an individual possesses an accurate understanding of the benefits and harms of screening; however, this appears to contradict my current understanding of informed choice wherein I argue that women should be provided an opportunity to understand such information, rather than be needed to possess the knowledge to make an informed decision. Although, in Chapter 3 (Study 1), I question the utility of a definition of informed consent (the language used within that paper) that privileges a set of standardised knowledge, and in Chapter 4 (Study 2), I provide an example of a shared decision-making process wherein the patient is afforded an opportunity to not discuss the benefits and harms of screening—ideas that align with my current understanding. The definitional shift in my thesis is illustrative of learning across the studies and reflect an early attempt at positioning myself within a feminist-informed framework. However, at this point in the thesis I was perceiving each paper as discrete separate parts, thus not fully carrying my understanding of informed choice over to the next paper. In now taking a wider view of my findings, I recognise these discrepancies as "dots" which link my current overall understanding of informed choice that only became clear when I integrated all findings into a coherent narrative. Overall, I regard discrepancies in language and definitions as time points that reflect upon my own learning of relational autonomy and shifts towards an identification with a feminist position that has occurred over the years in which this thesis was written.

Finally, within Chapter 6 (Study 4), both terms (i.e., informed consent and informed choice) are used. The term informed consent was used during interviews with GPs as the term represents an ethical and legal obligation within their profession (Royal Australian College of General practitioners [RACGP], 2018). However, the term informed choice was used in context with shared decision-making; a practice which more closely resembles informed choice. Shared decision-making stipulates that patients should be provided all relevant information, be provided alternate options (including not participating), and encouraged to ask questions and make a decision that aligns with their values (DuBenske et al., 2017; Hersch et al., 2017). As my analysis conceptualised shared decision-making as a process of informed choice, my supervisory team and I decided to use language which best suited the participants during interviews—informed consent. However, when writing the findings for the chapter, instead used the term informed choice to align with my overall recommendations discussed in Chapter 7.

1.5 Dominant Discourse Associated with Screening Mammography: Health, Risk, Gender and the "Pink Ribbon Culture"

In adopting a feminist relational perspective of informed choice, in this section I briefly review several socio-cultural and historical factors (i.e., processes) that influence women's decision-making within the screening mammography context. In doing so I draw from Foucauldian ideas of discourse and governmentality. According to the governmentality thesis, populations are no longer governed by rules and punishment, but instead by internalised discourses that are circulated and promoted by powerful institutions (e.g., medicine, mass media; Foucault 1978/2008; Willis, 2006). Within this framework, discourse is understood as interrelated sets of statements that form around societal values and ideals (Gibson et al., 2014). These statements create systematised ways of thinking, speaking, and acting for a particular population in a particular time (Foucault, 1972). In turn, this makes available subject positions or "ways of being" for individuals to take up (Foucault 1972; Willis, 2006). A comprehensive explanation of Foucault's relevant work, and associated scholars' work, is presented in Chapter 2. However, for now, this section is best understood with the knowledge that women's experience of breast cancer and screening is influenced by a range of socio-cultural, political and historical factors that provide and promote certain "ways of being." In addition, this section is best understood with the knowledge that I and other scholars, recognise that women play an active role in both reproducing and resisting the subjectivities (i.e., ways of being) offered by the dominant discourse (Gibson et al., 2015, 2016; Miner, 2017).

Researchers drawing from this perspective have identified several discourses that shape women's experience within the breast cancer/screening context and that make available certain subject positions (Gibson et al., 2015, 2016; Lau & Jaye, 2009; Willis, 2004; 2006). However, to my knowledge, none have explored the subject positions made available to women in the context of choice and screening mammography. I align myself with such researchers and review some of their work with the aim of introducing key processes that also appear to influence women's opportunities for informed decision-making about breast screening. The topics reviewed in this section are by no means an exhaustive list of influencing processes, however, I have chosen to review processes associated with health and risk, gender norms, women's experiences within the medical field, and the social construction of breast cancer and women within the "pink ribbon culture" because of their relevance to my project. Although I present each concept individually, it is important to note that the factors are interrelated. As such, I conclude the section with a brief summary that synthesises the discussed influences on women's experiences within breast cancer and screening mammography.

1.5.1 Health and Risk: The "Good" Healthcare Consumer

Prior research strongly suggests that cancer screening programs imply a social obligation to participate (Armstrong, 2007; Griffiths et al., 2010; Howson, 1999). According to Rose (2007), social obligations to engage in health behaviours may be linked to healthism—a wider social trend in the 21st century that heralded health as an ethical value. Crawford (1980) defines healthism as "the preoccupation with personal health as a primary-often the primary-focus for the definition and achievement of wellbeing; a goal which is to be attained primarily through the modification of life styles" (p. 368). While those adopting a healthism perspective may acknowledge that the cause of disease lies outside of the individual, it is, however, the individual's responsibility to find and engage with solutions to regain health (Crawford, 1980). As such, health is viewed as an individual choice, and a failure to achieve health is thus regarded as a failure of will, or ultimately of the self (Crawford, 1980). In this way, individuals are positioned as self-governing and responsible for monitoring their bodies (Crawford, 1980). Historically, healthism has roots in women's health movements and the rise of self-help and complementary medicine from the 1970s and 80s (Crawford, 1980; Moore, 2010). Within these movements, like healthism, individuals are valorised and seen as empowered for assuming responsibility for their health (Gibson et al., 2015). As stated by Gibson et al. (2015) the movement towards the empowered woman was borne from discontent with hegemonic medical practice and can be seen as challenging traditional notions of patriarchal power within the medical context. While for some individuals, healthism represents an opportunity to self-determine and govern one's health, it is important to be critical of alternate consequences. That is, states of health and unhealthy have become signifiers of normality and abnormality, and as such, have come to be a way in which a person's moral worth can be understood (Peterson, 1997).

The moralisation of health in Western societies is further understood through neo-liberalism, which is "a political rationality that tries to render the social domain economic and to link a reduction in (welfare) state services and security systems to the increasing call for personal responsibility and self-care" (Lemke, 2001, p. 203). Within neo-liberalism, individuals are cast as continuously employed within the business of living; they are seen as an entrepreneurial self whose responsibility is to ensure the preservation and production of one's human capital (Peterson, 1997). For example, it is an individual's responsibility to go to the gym to avoid illness, enabling them to work, provide for their family, and continue to be a tax-paying citizen—the state has no role in ensuring the individual remains healthy. By engaging in health behaviours, commonly termed as "self-care practices" within the literature, an individual mitigates their burden on society, and thus may be regarded as an autonomous and responsible citizen (Peterson, 1997). Individuals viewed as not engaging in self-care practices are thus seen as lacking self-control, lazy, careless, and as not fulfilling their role as a responsible citizen (Peterson, 1997). As such, engagement in health practices is seen as a choice of the virtuous individual. Within a neo-liberal framework, one wherein health is viewed as a choice and a desired commodity, individuals are constructed as consumers (i.e., experts of their own body) rather than patients (Gibson et al., 2015). Consumers are thus perceived to be in control; able to choose whichever products they desire in their pursuit of health (Lau & Jaye, 2009).

With the maintenance of health viewed as a moral imperative it makes sense that individuals and populations are preoccupied with calculating and managing health risk. The preoccupation with risk and risk management was arguably made possible by the dissolution of the traditional binary between health and illness in the 20th century (Armstrong, 1995). According to Armstrong (1995) this societal shift represents the beginning of surveillance medicine; a framework put forward by Armstrong (1995) that is premised upon "the problematisation of the normal" (p. 395). Within surveillance medicine states of abnormality and normality are similarly unstable and as such the body is continually "at risk" (Lau & Jaye, 2009). The consistent state of uncertainty leads individuals to engage in activity that, temporarily, renders their health future visible (Lau & Jaye, 2009). This is reflected in women's accounts of feeling provisionally reassured that they are breast cancer free post screening mammography (Griffiths et al., 2010). However, the nature of risk assessment is imperfect, and as such, the body soon resumes it's positioning as "at risk" and individuals are once again prompted to engage in risk-reducing/managing activities (Lau & Jaye, 2009). As stated by Lau and Jaye (2009), "the very nature of disease screening serves to remind people of the health that they might lack, while at the same time reminding them of the health that they could have" (p. 500). Neo-liberalism, healthism, and the inherent uncertainty in surveillance medicine, thus positions individuals to continually consume health products and avoid risk in the pursuit of wellbeing; a virtuous signal to others of one's responsibly to self, others, and society.

It is clear then that the pursuit of wellbeing is seen to contribute to a person's identity and that the body becomes "a project to be 'worked on' as part of a person's self-identity...attention to the 'healthy' body, therefore, is not simply about warding off disease. It is also concerned with how we present our bodies to ourselves and to others" (Petersen & Lupton 1996, p. 23). In interviews from 22 women with breast cancer, Gibson et al. (2015) reported that women drew on discourses of individual responsibility and empowerment to present themselves in socially desirable ways. For example, some women discussed "good" self-care practices they engaged in before developing cancer (e.g., monitoring their diet, exercising, attending regular mammography), which allowed them to position themselves as "good" women and ward off any blame for their diagnosis. The notion that engaging in self-care practices (i.e., breast self-examinations, cervical screening, and screening mammography) is a way to present oneself as responsible is echoed in other research (Armstrong, 2007; McGannon et al., 2016; Vahabi & Gastaldo, 2003). Conversely, research demonstrates that individuals viewed as not engaging in legitimised "self-care" practices are framed negatively. For example, some research suggests that health professionals position women as irresponsible for not attending cervical screening (Gibson et al., 2017; Sarkadi et al., 2004), while other research suggests that women may regard themselves as "foolish" for not attending screening mammography in light of breast cancer diagnosis (Gibson et al., 2015). Due to the moral meaning associated with "work on the body" it is unsurprising that the apparent failure to look after oneself can lead to blame (Lau & Jaye, 2009). The social ramification of a "wrong" choice within breast screening leads myself, and others, to critically consider the possibility of choice within the broader disease screening context (Gibson et al., 2015; Lau & Jaye, 2009). Further to this, some argue that the due to the virtuous undertaking of screening, rather than a means to acquiring health benefits, screening has become an end in itself (Lau & Jaye, 2009).

1.5.2 Gender Norms and the Medicalisation of Women's Bodies

Historically women have been regarded as the main caregiver within families, and as such, from a young age, are expected to engage with the role of nurturer and be responsible for the wellbeing of others (Vahabi & Gastaldo, 2003). Within traditional notions of femineity, it is thus important for women to remain healthy so that they may continue to care for others (Vahabi & Gastaldo, 2003; Willis, 2006). For example, in interviews with 32 Swedish women aged 40-49 years, Willis (2006) found that women's decision to attend screening mammography was tied to their family responsibilities—many discussed how their children relied on them, thus it was important to remain healthy, while one participant referred to herself as "the spider in the net of the family. If I'm sick, nothing works" (p. 140). Other research has echoed this idea—that women's compliance with screening recommendations is embedded within obligations to kin and friends (Howson, 1999; Willis, 2004). For example, in Howson's (1999) study women hoped that by complying with cervical screening recommendations, their kin and friends would be informed and persuaded to also attend (Howson, 1999), while women in Willis' (2004) study regarded attendance at screening mammography as a civic responsibility that ensured the service would return to their town, thus enabling more women's lives to be saved. Health management, in the form of cancer screening, "thus becomes part of the project of femininity and indeed good citizenship" (Gibson et al., 2017, p. 990).

The medicalisation of women's bodies represents another socio-cultural process that influences decision-making in the health prevention context. The term medicalisation refers to the "expansion of professional power over wider spheres of life, especially deviant behaviours, replacing religious and legal actors and their modes of social control" (Crawford, 1980, p. 369). In other words, over time, an increasing amount of social life and social problems have been subjected to the medical gaze (Lupton, 1997b). Second wave feminist writing opposed medicalisation and developed what is known as the medicalisation critique (Griffiths et al., 2010). A prominent figure within the critique, Ivan Illich (1975; as cited in Lupton, 1997b), asserted that medical intervention diminished, rather than improved, individual’s health and wellbeing—people now experienced side-effects from medical treatment and experienced a reduced capacity for autonomy over their healthcare. Other writers developed the critique to reveal how medicine was used as an agent of social control and to construct deviance within gender and sexuality (Griffiths, 2010). As such, from the perspective of the medicalisation critique, to be medicalised is seen as an undesirable state (Lupton, 1997b). However, other writers have debated this claim, and suggested that the assumption medicine has only ever oppressed women is over-simplistic (Griffiths et al., 2010). This research outlines how women have, and continue to, actively seek out medical intervention with the aims of reducing mortality, morbidity and pain (e.g., childbirth; Griffiths et al., 2010). In this way, women are not constructed as passive individuals controlled by powerful others, but instead they are part of negotiating their care, and the subject positions available to them. Aligning with my feminist-relational perspective, within this research I do not attend further to the moral debate of medicalisation, but instead recognise medicalisation as a process which contributes to the normalisation of subjecting women’s bodies to the medical gaze. More specifically, I briefly discuss here how women may be positioned to behave when under the gaze of powerful institutions of medicine (via health professionals) and technology (via the mammography machine).

Sociological research has long recognised the power imbalance that exists between doctor and patient due to patients’ lack of medical knowledge, the doctors perceived expertise (Lupton, 1997) and, the power imbalance between female patient and male doctor due to gender (Miner, 2017). Supporters of the medicalisation critique recognise these factors as entrenched within the medical encounter (Lupton, 1997b). As such, from this perspective patients were traditionally constructed as vulnerable to powerful doctors who seek to maintain the status quo (Lupton, 1997b). Although in contemporary accounts the construction of doctors as power-seeking and patients as perpetually vulnerable is contested (Lau & Jaye, 2009; Lupton, 1997b), the medical encounter is still recognised as site of social control (Lupton, 1997b). According to Waitzkin (1984; as cited in Lupton 1997) “the medical encounter is one arena where the dominant ideologies of society are reinforced and where individual’s acquiescence is sought” (p .339). While it is currently unclear *how* doctors act to reinforce dominant societal ideologies during the medical encounter, and thus create associated subjectivities for patients, there is support for the notion that they *can* reinforce health ideologies. For example, research has found that doctors are constructed as medical experts or “gatekeepers” of knowledge, and as such, are seen as influential of patient’s decision-making (Crawford, 1980; McGannon et al., 2016). More specifically, research has reported that the medical expert subject position often reinforces the values of healthism; a process that actively encourages women to take responsibility for their own health and enhances the importance of technological consumption (Peterson & Lupton 1996). In the breast screening context, healthism has been found to strongly encourage women to manage breast cancer risk and breast cancer with technological interventions (e.g., screening mammography, surgical or other medical treatments; McGannon et al., 2016; Peterson & Lupton 1996). I argue the reinforcement of dominant ideologies such as healthism and technological consumption are problematic in the breast screening context when they become privileged by health professionals. Thus, other possible discourses/health choices are negated and paternalistic practice is enacted.

Like reproductive technologies, screening mammography is considered by some feminist writers as a way to maintain control over women’s bodies with the power of medical science (Lupton, 1994). As such, the construction of screening mammography as the answer to women's fears has been criticised (Lupton, 1994). Concern is expressed for several reasons and relates to the displacement of women as the experts of their own body. For example, research suggest that women often give more credence to screening technologies detecting cancer than themselves (Griffiths et al., 2010; Lupton, 1992). Reliance on the mammography machine may lead women to experience a sense of false reassurance that they are breast cancer-free and displace practices such as breast awareness (Griffiths et al., 2010). Reliance on the mammography machine to see within the body also displaces the importance of women's embodied experience (Griffiths et al., 2010). The displacement of women as experts of their own bodies may undermine women's agency and bodily autonomy—women experience themselves as less able to "manage" their body and thus the breast becomes both fragmented and mystified, and in need of the medical-technological gaze (McHugh & Chrisler, 2015). Finally, the privileging of technology is argued by some as another way in which responsibility for health is placed on the individual (e.g., as the individual *chooses* to screen), and displaced from other institutions— such as government and inequalities in the environment that perpetuate health disparity (e.g., individuals with lower socio-economic status have fewer opportunities to engage in breast cancer risk-reducing behaviours such as maintaining a healthy weight and diet; King, 2004).

1.5.3 The Social Construction of Breast Cancer and Women

Over time the social construction of breast cancer has shifted from a stigmatised disease; a tragedy of which women best dealt with privately, to a highly publicised disease worthy of public debate and political engagement (King, 2004). In the latter construction a breast cancer diagnosis may be an affirmative life experience from which women emerge as survivors and are rarely constructed as patients or victims (King 2004). This shift is linked to the activism in the late 1980s which contributed to the construction of breast cancer through the “pink ribbon culture” (Gibson et al., 2015; Klawiter, 1999). As discussed by Sulik (2011) the pink ribbon culture focuses on “deeply held beliefs about gender and femininity, mass-mediated consumption and the [biomedical] cancer industry” (p. 9). Central to the pink ribbon culture is the construction of women in remission from breast cancer as survivors. While my project does not attend to the experiences of women diagnosed with breast cancer, or seek to further explore the subject positions made available to them, it is nonetheless important to briefly discuss survivors in the context of the pink ribbon culture. This is because women constructed as survivors are constituted by the same societal ideologies previously mentioned—discourses of healthism and individual responsibility, neo-liberalism, technological consumption and surveillance medicine (Gibson et al., 2014; McGannon et al., 2016), and as such, I argue that their experience is viewed, at times, as the success story of being a “good healthcare consumer” pre and post cancer diagnosis.

Against a backdrop of the pink ribbon culture the breast cancer survivor is constructed as a superwoman who fought breast cancer with style, strength, courage, and resolve (King, 2004; Sulik, 2011). Further to this, within their accounts of survivorship many women report becoming better people and learning to live in the present-moment with a sense of appreciation, and as such, breast cancer is re-framed as an opportunity for growth (Herndl, 2006). In addition, early detection practices, including screening mammography, appear important to the subject position of survivor. For example, in their critical analysis of how women with breast cancer respond to dominant health discourses, Gibson et al. (2015) recounted how one participant felt unable to occupy the subject position of survivor—the participant recounted that unlike her friend, who had also been diagnosed with breast cancer and urged her to attend screening mammography, she did not attend, and as such, she described feeling responsible for her perceived later diagnosis, and thus felt unable to likewise label herself a survivor (Gibson et al., 2015). It is clear then that early detection messages and survival is constructed through a discourse of individual responsibility (Gibson et al., 2014). For some women, a discourse of individual responsibility may be empowering (Gibson et al., 2014, 2015). Some women even report feeling that individual responsibility was necessary and adopted in response to the limitations of medical care (Gibson et al., 2015). However, for other women, such as the participant in Gibson et al.'s (2015) study, a discourse of individual responsibility may dually operate as a discourse of blame (Lemke, 2001).

In addition to blame, the subject position of breast cancer survivor within the pink ribbon culture may be unhelpful or limiting in other ways. For example, constructions of breast cancer survivors within the pink ribbon culture have been criticized as only representing white, heterosexual, middle class women, thus marginalising the experience of all women who do not identify with these identities (Gibson et al., 2016). Further to this, women with breast cancer are encouraged to entrench their cancer experience within a discourse of optimism; for some women this may provide hope, however for others, a discourse of optimism may serve to limit the possibility of coming to terms with their illness, negate the experience of incurable cancer (Gibson et al., 2015), and limit the range of emotional responses deemed appropriate (e.g., anger is absent from such discourses; Montini, 1996). With relevance to my project, I argue that the subject position of the breast cancer survivor within the pink ribbon culture may limit, or at least challenge the notion of choice with screening mammography. This is because of the relationships delineated between survivorship, individual responsibility, and early detection methods (i.e., screening mammography) within the subject position. It is thus not surprising that, as recognised by Lupton (1994) in her analysis of Australian media representations of breast cancer, that women only received press attention when they were portrayed as "as triumphant, brave fighters against breast cancer, living examples of the victory of medical intervention, extolling the benefits of early detection" (Lupton, 1994, p. 83).

1.5.4 Summary

In this section I have reviewed several dominant socio-cultural, historical, and political processes that shape an individual's decision-making within preventative healthcare, with a specific focus on screening mammography. I join other researchers in recognising that health preventative initiatives, including the Australian national screening mammography program, represent subtle forms of governance (Howson, 1999). Within this framework of governance, health is constructed as an ethical ideal, one for which the responsibility to gain/maintain health lies solely on the self and their perceived choices (Crawford, 1980; Rose, 2009). Through an intersection of neoliberal, gendered and surveillance norms, women are expected to subject their breasts to the medical gaze—wherein health professionals reinforce societal values, and medical technology assumes expertise over the body (Griffiths et al., 2010; McGannon et al., 2016). Screening mammography then represents a consumable opportunity in which the perpetually "risky" female body can be worked on (Lau & Jaye, 2009). Such work on the body provides a virtuous signal to self and others, thus enabling belongingness to the responsible citizens club and, perhaps if ever diagnosed with breast cancer, particular survivorship narratives. For women, such responsibility is tied with notions of traditional femininity which further the importance of risk-reduction—a woman must remain healthy so that she may continue to care for others (Lupton, 1994). Indeed then, screening mammography becomes prescribed in the pursuit of femininity and good citizenship (Gibson et al., 2017). Failure to do so leaves women potentially vulnerable to social ramifications such as blame, shame, and guilt (Moore, 2010). However, as stated by Foucault (1978/2008), where there is power, there is resistance. And as such, women may resist dominant discourses in screening mammography (e.g., by perhaps choosing to not attend). In taking a critical stance it is imperative to identify where such opportunities are facilitated and where they are hindered. In other words, to identify where choice to attend screening mammography is enabled and where is it impeded.

1.6 Rationale

The research reviewed demonstrates the contention surrounding screening mammography—the uncertainty regarding the benefit and harms posed to asymptomatic women (Gøtzsche & Jørgensen, 2013), and the potential that screening, rather than a means to acquire health, has become an end itself; a way in which a responsible and virtuous citizen is constituted (Lau & Jaye, 2009). I argue that the social and moral obligation related to screening mammography limits women's opportunity to choose not to screen; an arguably "reasonable" response to the contested evidence. The importance of supporting women to make an informed decision about breast screening has also been recognised in policy. For example, Cancer Council Australia's (n.d) evidence-based policy priorities include a commitment to "ensure informed consent among BreastScreen participants" (https://wiki.cancer.org.au/policy/Breast_cancer/Policy_priorities).

While efforts to support informed decision-making have been made—the development of decision aids to increase women's knowledge (Hersch et al., 2015; Mathieu et al., 2010; Mathieu et al., 2007), critical analysis of print and web media that highlight misinformation (Jørgensen & Gøtzsche, 2004, 2006; Schwartz & Woloshin, 2002; Steele et al., 2005), and exploration of barriers to shared decision-making in the primary care setting (Fowler et al., 2013; Gunn et al., 2015; Hoffman et al., 2010; Joseph-Williams et al., 2014), I argue that, while they are important, they are insufficient in supporting women to make an informed choice in the breast screening context. This is because such efforts appear to adopt a biomedical conceptualisation of informed decision-making (i.e., informed consent) which limits the role of socio-cultural, historical and political processes on women's decision-making (Donchin, 1995). As such, within this project I adopt a feminist-relational framework of informed decision-making—informed choice. Within this perspective, I am able to challenge the entrenched rationality within the biomedical framework of informed decision-making—that individuals make health care decisions based on calculated risks and evidence-based information (Lau & Jaye, 2009), and critically consider the role of socio-cultural processes in facilitating or hindering opportunities for an informed choice within the breast screening context.

Efforts to support women in making informed and autonomous health care decisions are important for several reasons including, the recognition that health prevention initiatives (e.g., BreastScreen Australia) act as a form of social control (Howson, 1999; Nettleton, 2006). With respect to the breast cancer and screening context, I have reviewed literature that suggests women are socially and morally obligated to attend screening through discourses of healthism and individual responsibility, and gender and surveillance medicine norms (Crawford, 1980; Griffiths et al., 2010; Howson, 1999; Lau & Jaye, 2009; Vahabi & Gastaldo, 2003). Failure to engage with screening mammography may then engender social consequences such as shame, guilt or blame (Moore, 2010). Such findings challenge the notion of choice within screening mammography. Other researchers express concern that politically and socially derived enthusiasm for disease screening may obscure the true health needs of women. For example, Lupton (1992) argues that the health issues reported by media and government as important differ from those reported by women. Research indicates the problems most frequently mentioned by women relate to stress, tiredness, arthritis, being overweight, and financial strain (Brown & Doran, 1996; Charles & Walters, 1994). As such, Lupton (1992) suggests that the social and political enthusiasm for screening mammography may actually direct scarce financial resources away from more pressing needs and priorities (Lupton, 1992). Further to this, Lau and Jaye (2009) document how enthusiasm for disease screening has the potential to "expose people to poor standards of medical practice, to the premature diffusion of technologies, as well as to the exploitations of commercial companies whose primary interests might have been monetary profits rather than genuine health benefits." (p. 502). Overall, I align myself with researchers who regard the lack of informed choice within screening mammography as undermining women's autonomy and recognise the potential social and political consequences (Lau & Jaye, 2009; Lupton, 1992; Ward, 1999). However, I refrain from judging women's decisions to participate or not participate in the screening mammography within a moral framework. Instead, I seek to critically examine, and thus advocate, for a diversity of experiences to be equally supported within this context.

In my project, I aim to explore how cisgender women are supported in making an informed choice with regards to screening mammography through a critical analysis of the discourses used by women, the media, and health professionals. To date, the discourse of screening campaigns, advertisements, and invitations have been analysed (Jones, 2004; Jørgensen & Gøtzsche, 2004, 2006) and the way in which mass media constructs women in relation to breast screening is briefly discussed (Lupton, 1994; McGannon et al., 2016). However, analyses of media focused on determining bias and employed simplistic analytic techniques or neglected to consider the implications of their critical analysis to informed decision-making practices. Several studies have examined the effects of socio-cultural, historical, and political discourses on women's meaning making in relation to breast cancer and breast screening (Gibson et al., 2015; Griffiths et al., 2010; Willis, 2004, 2006). However, these studies differ from the current project in several ways. For example, Gibson et al.'s (2015) study focuses on examining how women with breast cancer make sense of their illness through a neo-liberal discourse—I instead focus on the experiences of asymptomatic women, and how neoliberal and other discourses are used to make meaning (i.e., provide opportunities) of choice with screening mammography. Like my project, Griffiths et al. (2010) study focus’ on women’s discursive accounts of breast awareness and screening mammography, however, their study neglects the experiences of women who do not participate in such practices and they do not discuss the implications of their findings to women’s opportunities for choice. The aims of Willis’ (2004, 2006) studies closely resemble my own—to explore the influence of health discourses on women’s decision-making within the breast screening context. However, dissimilar to my study, Willis’ (2004, 2006) studies focus on interviewing women aged 40-49 years; women described as consciously choosing to engage with national screening programs. Thus, the experiences of women actively targeted for national screening programs (women aged 50-74 years), and those who do not attend, are missing. With respect to the discourses of health professionals, my project builds on work such as Parker et al.’s (2015a, 2015b). This research focuses on examining the influence of differing ethical values and epistemological positions on communication of breast screening (Parker et al., 2015b, 2015c). My project differs by examining a wider scope of socially embedded concepts, and by paying closer attention to how discourses work to constitute health professionals and women in relation to choice within screening mammography.

Overall, my research adds to existing literature in terms of exploring how socio-cultural, historical, and political processes influence women in relation to breast screening. In addition, my research provides novel insights into the discourses used by women targeted by BreastScreen Australia, non-attenders of screening, health professionals (i.e., GPs specifically), and mass media to construct choice within screening mammography. The findings of this study will create a clearer understanding of the socially constructed autonomy supporting and undermining factors that may influence a woman’s choice to be screened.

This may have implications for strategies aimed at ensuring informed choice and autonomy is exercised before engaging in breast screening.

Although I align myself with a feminist-relational informed understanding of autonomy, I do not abandon the biomedical perspective completely. I believe an informed choice still requires an accurate understanding of benefits and harms. As such, my project also aims to be the first study to synthesise research relating to women's knowledge of breast cancer and breast screening. The findings of the systematic review will generate a clearer understanding of misconceptions and may be useful when developing strategies to improve breast health communication and informed decision making.

1.7 Terminology

Attenders	A woman who screens biennially.
Autonomy (relational)	The term used to represent the feminist-relational and procedural informed concept of autonomy.
Biomedical autonomy	This term is used to represent the conditions for autonomous decision-making as understood through a biomedical lens.
Breast screening	Used within the thesis interchangeably with screening mammography; digital mammograms used to examine asymptomatic women's breasts for screening purposes.
Cancer/disease screening	Medical tests that look for early signs of disease in asymptomatic populations.

Cisgender	Refers to a person whose gender and sense of identity corresponds with their birth sex
Healthism	A health trend prominent in the 21st century that positions health as an ethical value; health is most often obtained through the modification of lifestyle, while ill-health is regarded as a failure to care for the self.
Informed choice	Informed choice requires that an individual should make a decision based on an accurate understanding of the benefits/harms of the procedure/intervention, and within an environment that supports an autonomous decision as informed by the feminist-relational characterisation of autonomy.
Informed consent	Informed consent requires that an individual is seen as a competent decision-maker, is provided all relevant information, understands the information, and voluntarily consents to the practice/procedure. It is informed by biomedical conceptualisations of autonomy.
Informed decision-making	The process of making an informed choice.
Neo-liberalism	A political rationality that positions the healthcare system under an economic domain; governments are then less responsible for the maintenance of health, and

	individuals are cast as expert consumers free to choose their health care.
Non-attender	A woman who screens less frequently than biennially (i.e., 3+ years) or who has never screened.
Screening mammography	Digital mammograms used to examine asymptomatic women's breasts for screening purposes.
Shared decision-making	An interaction between patient and GP wherein both parties express preferences and come to a decision.
Surveillance medicine	This term represents the blurring of the dichotomy between health and illness and an increasing focus towards monitoring risk within a population.
The pink ribbon culture	This is a term used to describe the dominant illness culture within breast cancer. Relevant to my project, the pink ribbon culture draws strongly from neoliberal discourses thus positioning the diagnosis, treatment and recovery of breast cancer as the individual's responsibility.

1.8 The Researcher

Growing up as a woman in Australian Western culture, I have, on many occasions, been encouraged to monitor my breasts for breast cancer. At the time of starting my doctoral research program, as a 21-year-old woman, I was encouraged to practice self-checks (i.e., monthly breast self-examinations). Specifically, it was an encouragement to self-check from my mother, towards the end of my third year of my Bachelor of Psychology that planted the seed for this research project. My mother's prompt led me to consider if young women engage in the practice of monthly self-checks. This question became the cornerstone of a scholarship application for Cancer Council Australia where I applied for a scholarship to support my research during my honours year. Although I was unsuccessful in my application, a few weeks later, Professor Christobel Saunders, a board member of Breast Cancer Network Australia (BCNA), Cancer Council Australia, and of the committee that reviewed my application, emailed me to talk further about my proposal. In the next fortnight, I met with Professor Saunders and learnt that breast self-examinations were no longer a practice recommended by BCNA or Cancer Council. Research had concluded that the practice of self-examinations had little clinical significance on mortality rates and instead breast awareness was to be recommended (McCready et al., 2005). Breast awareness advocated for women to be familiar with their breasts and differed from self-examinations by not denoting specific time frames (i.e., in practicing breast awareness women are not encouraged to examine their breasts once per month, and instead, women are encouraged to be familiar with the shape, look and feel of their breasts; Thornton & Pillarisetti, 2008). I, my honours supervisors, and mother, were surprised to learn of these changes from Professor Saunders, and it led us to question what else do we not know about breast health? And more importantly question, why do we not know?

My honours project sought to explore post-menopausal women's experiences with breast health practices in efforts to understand if congruence existed between recommended practice and women's breast health experiences (Seaman, Dzidic, Breen et al., 2018). Results indicated that participating in BreastScreen Australia and engaging in self-examinations were the "right" things to do. Interested by the moralisation of breast health behaviours, my supervisors and I began to question the role of such moralisation in women's decisions to engage in practices. In turning to the literature, I encountered a wide field examining factors which influence healthcare decision making, often citing models such as the theory of planned behaviour, health beliefs models, or research which sought to develop and assess decision making tools. Although the role of “others” is mentioned in these theories, they neglect the influence of past and present socio-cultural, historical, and political ideologies specific to preventative medicine and women.

Informed by the work of Michel Foucault, and his beliefs in the power of language, I began to understand how power, thus dominant societal ideologies, moved through language. As such, my research focuses on how “ways of being” are created through discourse. However, Foucault, while vital to my research, only offered a way to analyse discourse, and critically question its effects; he refrains from making distinctions between helpful or unhelpful forms of power. As such, I adopt a feminist perspective to ground my argument that power which limit’s women’s autonomy is undesirable, and thus, efforts to dismantle such power should be made (Ells, 2003; Handa & Sharpe, 2015). Therefore, within the breast screening context a diversity of experiences and choices should be equally supported.

All researchers should be concerned with how they position themselves in relation to their work; that is, as insiders or outsiders. A researcher adopting the positioning of an insider typically resembles the group under study in some way (Merton, 1972). For myself, this was my expression of identity as a woman. Aligning with the literature, I experienced several benefits from being positioned this way—increased insight and empathy into the experiences of being a woman potentially increased my participants’ willingness to openly discuss women’s health issues with me (Dwyer & Buckle, 2009; Gair, 2012). However, in other ways, I was also positioned as an outsider—my age positioned me outside of the target population for BreastScreen, and the fact that I had not known loved ones who had developed breast cancer, which appeared to be a common experience for women. Although, I believe this distance enabled me to guard against over-identifying with the normalisation of breast screening, and uncritically endorse the construction of the practice as life-saving. As such I was able to maintain a critical and curious stance not afforded to those on the inside (Dwyer & Buckle, 2009; Gair, 2012). This meant that by not assuming women *should* screen, I was able to question *why* do women feel they should screen? And in turn, advocate that women *should* have an opportunity to make an informed choice. As such, I adopted both insider and outside perspectives (Breen, 2007).

1.9 Research Objectives

The overall aim of this research was to explore if cisgender women were provided opportunities to make informed decisions in the breast screening context. In recognising that an informed decision is one in which an individual is provided an opportunity to consider evidence-based information, and supported to exercise autonomy, I focused on understanding what women knew about screening, and how discourses, as used by women, mass media, and GPs provided certain subject positions and/or opportunities for women to make informed decisions in the breast screening context.

The research objectives were to:

1. Address gaps in the literature through conducting a systematic review of existing literature examining women's knowledge of breast screening.
2. Examine how women, health professionals, and the media construct choice in mammography.
3. Evaluate whether the discourses used by, and/or subject positions available to, women, health professionals, and the media are autonomy supportive or undermining.
4. Inform clinical practice with cisgender women and make recommendations to contribute to improved communication and policy to support informed choice.

1.10 Research Studies and Questions

The research was conducted through four studies with each addressing a unique research question. Further detail on each study is provided in Chapter 2.

Study 1: ***Research question:*** What do women know about screening mammography?

Study 2: ***Research questions*:** How do attending and non-attending women aged 50-74 discuss screening mammography? What subject positions are made available in this discourse? What are the implications for informed choice?

Study 3: ***Research questions:*** What subject positions are made available to women through discourses on screening mammography presented within Australian television news channels, and national /state newspapers from the last two years? What are the implications of the subject positions/discourse to women's possible experiences of informed choice?

Study 4: ***Research questions:*** What discourses do GPs draw on when discussing screening mammography? How do the discourses GPs draw upon influence the practice of shared decision-making and informed choice?

1.11 Structure of the Thesis

This thesis is presented in a hybrid format, and includes three traditional thesis chapters—an introduction, methodology, and general discussion chapters; two chapters as published manuscripts; and two chapters written as unpublished manuscripts. Each chapter begins with a brief overview to assist in orientating the reader. A master reference list for all chapters and the appendices are located at the end of the thesis. Where a chapter is presented as a published manuscript, approval was obtained by the publisher to include the article in the submitted manuscript form (see Appendix B and C). Tables and figures with published manuscripts have not retained their numerical positioning, and like tables and figures presented in chapters and unpublished papers, are numerically ordered according to appearance in the thesis.

The thesis began with Chapter 1 which presented a brief review of screening mammography, broadly and within Australia, an in-depth review of several relevant ethical perspectives, with application to the breast screening context and, a summary of socio-cultural, historical, and political processes associated with health, risk, gender, and the pink ribbon culture. The chapter concluded with the rationale, key terminology, my position as the researcher, the research objectives, and a review of the thesis structure.

Chapter 2 presents the overarching research design and epistemological position adopted in the thesis. The chapter then offers a brief review of Foucault's work pertaining to relevant concepts to the thesis, before reviewing the main analytical technique used for studies 2 to 4—Foucauldian Discourse Analysis. The chapter concludes with a strong rationale for incorporating feminist perspectives with Foucault's work, a summary of each chapter and ethical considerations relating to Studies 2 and 4 (Chapters 4 and 6) in which data was collected from human participants.

Chapter 3 is a published manuscript that presents the first study in the thesis, a systematic review of women's knowledge of screening mammography. Following the chapter overview, the manuscript presents the debate surrounding the efficacy of screening mammography and highlights the rationale of the study as being the first study to systematically review what women know about screening; an endeavour discussed as pertinent to enabling informed decision-making. The article then describes the methodology, followed by a detailed report of study characteristics/quality and study findings in the results section. The article highlights the variability in what women know about screening.

Chapter 4 is a published manuscript and presents the second study conducted in the thesis which involved interviewing 16 women aged 44-72 years. This chapter discusses informed decision-making as a process influenced by the socio-cultural environment and highlights the lack of research specifically exploring how the social of construction of screening may impact choice. The method section, findings and interpretations, and discussion are then presented. Overall, the chapter demonstrates existence of discourses and subject positions which serve to limit the opportunity for women to make an informed choice in the breast screening context.

Chapter 5 is the third study in the thesis and is presented as a publishable manuscript. Following the chapter overview, the manuscript argues the need to conduct a critical analysis of news representations of screening mammography, in light of mass media being recognised as a key socio-cultural factor that can shape women’s health experiences. The method section, which details the systematic process of data collection, extraction, selection and analysis that was conducted is then presented, followed by the findings and interpretations, and discussion sections. The study reports that three subject positions were made available to women in mass media, and that inherent to all, was an expectation that women should screen.

Chapter 6 is also presented as a publishable manuscript, and is the final study conducted in the thesis. The study interviewed 12 GPs in the aim of identifying the discourses used when discussing screening mammography. The findings suggest the importance of shared decision-making during the clinical encounter, that it seldom occurs in practice, and highlights the need to expand work that has identified socio-cultural processes that influence shared decision-making practices. The manuscript then presents the method, findings and interpretation, and discussion section. Overall, the manuscript identified that GPs draw on several discourses when discussing screening mammography, with some facilitating opportunities for shared decision-making, while others, hindering such opportunities.

Chapter 7 concludes the thesis by synthesising the findings from Chapters 3 to 6 (Study 1 to 4), and contextualising them within prior research and methodology as presented in Chapters 1 and 2. Through the integration of key findings with empirical literature, this chapter also provides recommendations for clinical practice and future research that facilitate women in making informed decisions in the breast screening context. In addition, through the integration of literature and key findings I consider what it could look like if the dominant understanding of autonomy was altered. The thesis concludes with a discussion on the strengths and limitations of the research, before presenting the final conclusions.

Chapter 2: Research Methodology

2.1 Chapter Overview

In this chapter, I present the research methodology I used to explore the construction of screening mammography, choice to screen, and associated implications for informed decision-making. I begin by presenting a brief summary of each study, with attention given to highlighting how the studies relate to one another. Next, I discuss social constructionism as the theory of knowledge underpinning the research. I then provide a discussion of Foucault’s work on discourse, knowledge, power, and governmentality; ideas that I use to guide my analytic technique. In this section, I also briefly note the parallels between Foucauldian informed theory and social constructionism to highlight the approaches as complementary. Next, I discuss how Foucauldian-informed ideas and feminist theory work together to inform the overarching framework for this project. This is followed by a brief introduction and explanation of my dominant analytical technique—FDA. I conclude the chapter with a discussion of the ethical considerations pertinent to the studies involving human participants (Study 2; Chapter 4 and Study 4; Chapter 6).

2.2 Research Design

Within this project, I used qualitative methods such as narrative synthesis, one-on-one, face-to-face/telephone and semi-structured interviews, and adopted a social constructionist epistemological position to explore the construction of choice within screening mammography. I also drew on feminist theory, specifically accounts of procedural autonomy, and the work of French philosopher Michel Foucault to guide my understanding of the research problem, analysis, and discussion of findings. As such, my theoretical positioning may be thought of as a Foucauldian informed feminist—I recognise and attend to the workings of power, and argue that women should be provided with choice in the breast screening context.

2.2.1 Summary of Studies

The research adopted a sequential qualitative design to better understand factors which facilitate and undermine women's ability to make an informed choice in the breast screening context (Figure 1). The research commenced with a systematic review of women's knowledge of screening mammography which employed the qualitative technique of narrative synthesis for data analysis. It was anticipated that the findings of Study 1 (Chapter 3) would contribute to developing strategies to improve breast health communication to support informed choice. Studies 2, 3, and 4 (Chapter 4, 5, and 6) used FDA as the analytic technique and served to explore how screening mammography and choice is socially constructed from three key sources—women, mass media, and GPs. Although each study, and its analysis occurred separately, I anticipated that the views of the women interviewed in Study 2 (Chapter 4) would inform sampling for Study 4 (Chapter 6) by identifying health professionals with whom they discuss screening. The reason for using women's views to inform sampling in Study 4 (Chapter 6) was to ensure I engaged health professionals who have a direct role in communicating breast screening discourse with women and meant that participants in Study 4 were GPs. It was also anticipated that the participants from Study 2 (Chapter 4) would determine the sources of media under analysis, to again ensure relevance of analysed discourse, in Study 3 (Chapter 5). Women often identified news forums (television, magazine, and newspapers), websites such as Cancer Council Australia, and search engines such as Google. For copyright law reasons, I decided to analyse television and newspapers discourse only; a decision supported by Industry and Market Research Company, Roy Morgan, which indicated the continued use of such mediums by Australians ("It's official: Newspaper masthead readership is up 3.2% to over 16 million”, 2018; “Australian Newspaper Readership, 12 months to June 2019”, 2019). The findings of Study 2, 3 and 4 (Chapter 4, 5 and 6) provide commentary on the social construction of screening mammography and choice, enable consideration of the implications to informed choice and, like Study 1 (Chapter 3), contribute to recommendations for future breast health communication (see Chapter 7).

I present each study’s findings independently in Chapters 3 to 6, followed by a chapter that provides an integration of all findings to address the overarching aims of the project and recommendations for future communication and practice (see Chapter 7).

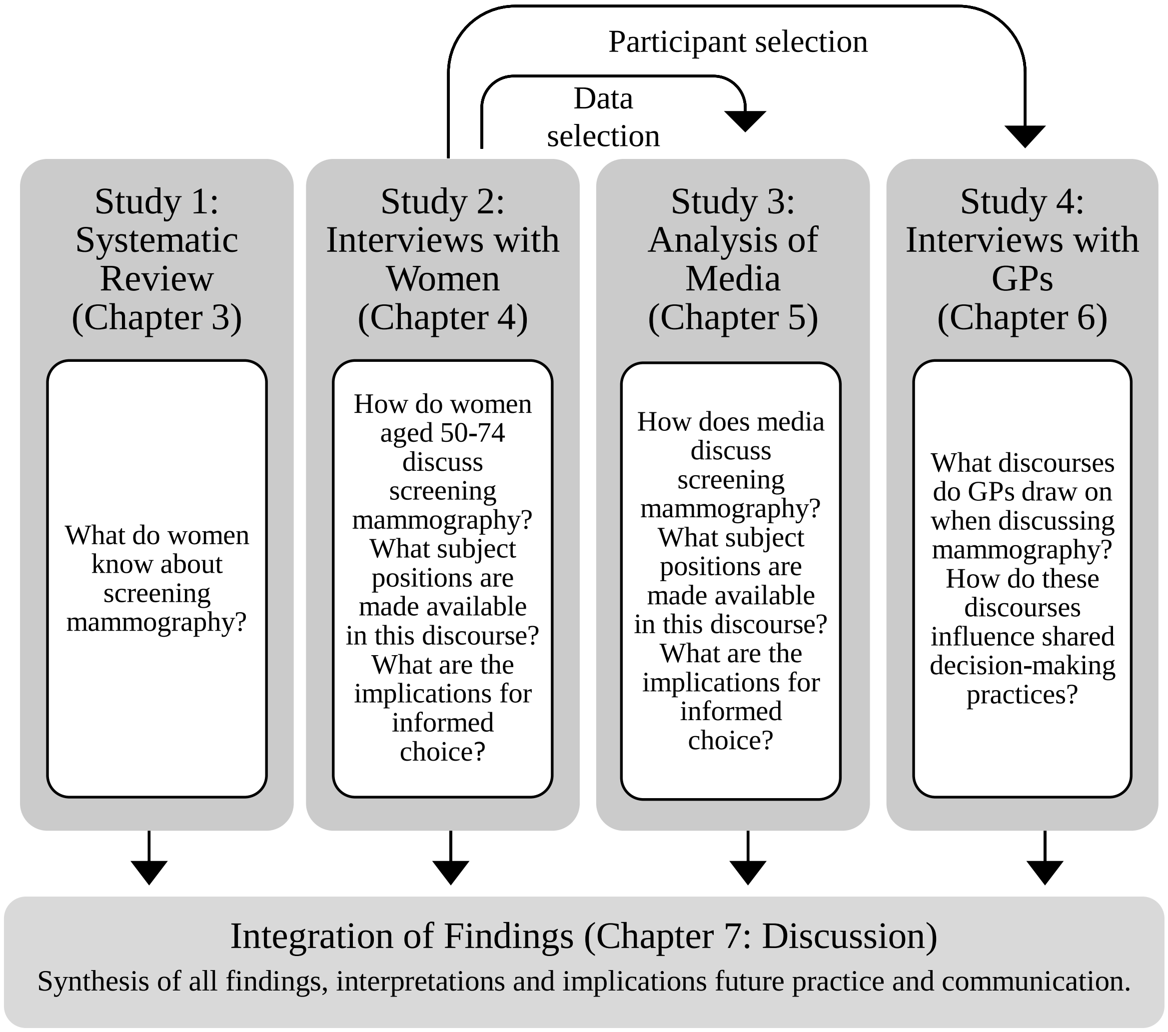

Figure 1. Summary of research process and research questions

2.2.2 Social Constructionism

According to Gergen (1985), social constructionism recognises that “a great deal of human life exists as it does due to social and interpersonal influences” (p. 265). Although there are many variations of social constructionism, I align with those who believe that realities are socially constructed through language (Galbin, 2014; Gergen, 1985). As recognised by Galbin (2014), what “counts” as social constructionism is, in part, driven by the researcher’s aims; however, before explaining my perspective in more detail, I will discuss some common key features of social constructionism.

The first feature of social constructionism is its critical stance towards traditional paradigms of knowledge such as empiricism and positivism (Burr, 2015; Galbin, 2014). Instead, social constructionists believe that knowledge is (re)shaped by social processes, rather than “discovered” in the natural world (Burr, 2015). This belief underpins the second key feature of social constructionism—that the way a person sees and understands the world is shaped by that person’s culture and history (Burr, 2005). More specifically, understandings are shaped through the interactions of people and groups, which over time, come to form certain mental representations of the self, others, and the world (Galbin, 2014). The third feature of social constructionism is its drive to be critical of the taken-for-granted assumptions in the world. For example, social constructionists may specifically seek to question if and how certain knowledge serves the interests of some groups over others (Galbin, 2014). The fourth feature of social constructionism is the belief that each unique social construction opens unique possibilities for actions (Burr, 2005).

To expand on these key features and their application to my research, I will articulate my social constructionist position. I believe that meaning is not a property of events and objects and is instead created through the shared understandings of that event/object (Galbin, 2014). A shared understanding is typically communicated via language, which means that we “exist” in language (Gergen, 1985). As such, within my project I am interested in how people (e.g., women, producers of mass media, and GPs) construct their world through language (i.e., discourse), and understand social processes as embedded within language. Over time, social processes become so strongly agreed upon or habituated, that they may appear as facts that provide roles for people to “take up” or “play out” (Galbin, 2014). I am interested in critically questioning the consequences of these facts and roles in advantaging or disadvantaging certain experiences (i.e., informed choice; Galbin, 2014). Thus, the facts and roles that come to be embedded in the fabric of society are not random, and instead are culturally and historically located (Burr, 2005). As such, time and context are important to consider and document.

In summary, my social constructionist position is one that rejects the notion of a universal truth, acknowledges the possibilities of many realities, articulates that realities are constituted through language, locates realities in their cultural and historical context, and seeks to critically question the impact socially constituted realities have for individuals and groups.

2.2.3 Foucault: Discourse, Power, Knowledge and, Governmentality

Michel Foucault was a French philosopher and historian who sought to critique historical reason and discover the relations between disciplines, knowledge, and social practice (Rainbow, 1984/1991). In this section, I focus on the concepts he developed that have shaped my methodological approach, FDA. These concepts include Foucault’s ideas on discourse, power/knowledge, and governmentality. By doing so, I aim to explain the theoretical backdrop to this project, enabling the reader to see how my ideas have formulated, and how they will later be discussed in the concluding chapter (Chapter 7).

2.2.3.1 Discourse

According to Foucault, discourse can be explained as "certain ways of speaking" (1972, p. 193). Foucault's conceptualisation of discourse differs from the understanding traditionally used in discourse analysis—rather than language seen as a cultural resource from which the speaker can draw, he emphasised the constructive nature of language in shaping how a speaker can think, speak, and act (Burr, 2105). In this sense, discourse is seen as regulatory social practice that creates certain "ways of being" or subject positions (Foucault, 1972).

Aligning with the ideas of social constructionism, Foucault (1972) regarded discourses as socio-culturally and historically bound. As such they are thought to represent systematised ways of thinking, speaking, and acting for a particular group of people in a particular point in time (Willig, 2013). For example, Western society has seen a shift in the way mental health is conceptualised. A widely favoured discourse in Western society in the 21st century conceptualises mental health problems through a biopsychosocial model; however, in the past mental health had been conceptualised as resulting from sin or possession by evil spirits (Burr, 2015).

Although Foucault refrained from explicitly adopting a social constructionist position, both Foucault and those adopting a social constructionist position are dubious of "absolute" truths, and as such argue that at any one time multiple discourses about a discursive object are available (Burr, 2015; Foucault, 1972). For example, Burr (2015) provided the following illustration using the discursive object of fox hunting; fox hunting can be placed in one of the two following discursive locations—hunting as an environment saving practice or hunting as an inhumane sporting practice. As discourse constitutes social practice, each version enables particular thoughts, words, and actions. For example, the hunter (i.e., subject) bound within a discourse of environmental sustainability may talk about their hunting as saving the planet through the eradication of non-native pests and be met with admiration and gratitude from others, while the hunter bound within a discourse of ethical animal conduct may speak of their hunting as a test of skill, patience, and endurance against an animal, but be met with disproval and statements such as “killing animals is immoral.” In this way, discourse has not merely described an object, but constituted the social practices (McNay, 1994). As such, discourse is inextricably linked with the exercise of power; as Foucault (1978/2008) asserted, “discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart” (Foucault, p. 100).

2.2.3.2 Power/Knowledge

For Foucault (1980), power and knowledge are linked—he joined the two words to highlight that one cannot occur without the other. For example, Vahabi and Gastaldo (2003), in describing Foucault’s work, noted, “it is impossible for power to be exercised without knowledge and for knowledge not to create power” (p. 250). Foucault’s position on power can be understood through the four following concepts—power cannot be possessed, power is productive, power disciplines the body, and power engenders resistance (Stevenson, 2014).

Rather than conceptualising power as a top-down process, Foucault (1980) invoked a “capillary” (p. 96) metaphor to describe power. By this he meant that power is neither here nor there, but rather consistently circulating in a net-like fashion through social relations (Foucault, 1980). As such, we are perpetually enmeshed in power relations that operate upon us (Ells, 2003). It is for this reason that Foucault (1977) believed the analyses of power should concentrate on the point of application of power rather than the perceived possessors of power. As such, within my project I focus on examining the discourses of women, mass media, and GPs—I regard the discourses produced as the effects of power.

Foucault (1977) strongly asserts that power is both restrictive and productive. He argued that knowledge production is a way to exercise power and to define ourselves and others (Foucault, 1977). For example, a woman engaging in screening mammography is seen as seeking and producing knowledge (e.g., whether or not she has breast cancer), which in turn provides her power and status; she is able to construct herself as a risk-reducing responsible citizen. Through time, certain “truths” and truth-tellers (e.g., medical experts, governments, and the mammography machine) become privileged over others, thus legitimised within the population as social norms and experts. In this way, certain discourses and institutions become, through their continued production of knowledge, as more powerful than others (see Chapters 4, 5, and 6).

Foucault’s analysis of power draws attention to the way in which power relations discipline the body/populations (Ells, 2003). When used in this context, discipline does not mean to punish, but instead represents the ultimate goal and effects of discipline—normalisation (Foucault, 1977). A key instrument within disciplinary power is surveillance (Foucault, 1991). He noted that, in the eighteenth century, surveillance began to replace strong forms of corporal punishment (Foucault, 1991). The replacement of punishment to surveillance is because to place subjects under surveillance appeared more beneficial and profitable than to punish them. Foucault (1991) described how, within contemporary society, surveillance has become internalised to the point that each individual has become their own overseer (Foucault, 1991). He likened this internalisation to the Panopticon—a system of prison surveillance designed by Jeremy Bentham in the eighteen century. Within this system, prisoners were uncertain whether or not they were being watched and, as such, they began to police their own behaviour continuously (Foucault, 1991). In this way, prisoners began to self-regulate their behaviour to align with desired standards (i.e., norms) imposed by those with power in society.

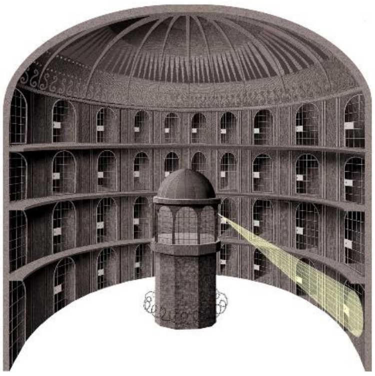

Figure 2. A diagram of the panopticon

Note. *From Surveillance State,* by The New York Times (https://www.nytimes.com/2013/07/21/books/review/the-panopticon-by-jenni-fagan.html) Copyright 2013 by Tom Shone

Fields such as epidemiology and medicine can be considered as modern disciplinary systems that regulate and control a population in a similar way; through the use of surveillance, knowledge production, and the normalising gaze. The fields may be considered modern disciplinary systems because the act of surveillance, thus analysing of a population, produces knowledge. The knowledge produced is then used to categorise what is normal and what is deviant—thus establishing norms (Armstrong, 2004). According to these norms, the population can then be divided into two subgroups; those that can, and those that cannot, contribute to society (Rose, 1996). The division of the population then enables society and citizens to judge themselves, and others, against their capacity to engage in responsible citizenship—their efforts to remain or return to "normal" (Ells, 2003; Rose, 1996). Through their efforts to remain or return to normal the individual is willingly reflecting upon and reproducing the dominant ideas of the day. Therefore, power is considered as productive, in that it produces certain types of citizens, rather than as repressive (Willis, 2004). As such, in contemporary society, individuals are controlled through the power of the norm (Rose, 1996). In this way, behaviour is not regulated through overt repression, but instead through internalised standards of normalcy. Social control is therefore diffused through society and "governing at a distance" is achieved (Armstrong, 2005; Rose, 1996).

However, according to Foucault (1978/2008), "where there is power, there is resistance" (p. 95). This is because for power relations to come into existence there must be freedom on either side—without the possibly of resistance, there would be no power (Armstrong & Murphy, 2011). Like power, resistance also has no single locus of control and is diffused throughout society (Ells, 2003). The diffuse nature of power means that resistance can take any form, at any time and, in any place (Armstrong & Murphy, 2011). Resistance can be overt and include behavioural responses, such as choosing to not engage in a recommended health practice, or conceptual, such as a rejection of the dominant discourse within which the health practice is embedded (Armstrong & Murphy, 2011). It is important to critically consider the nuances of resistance; to not assume that engagement in a practice represents acceptance of dominant discourses or that non-engagement represents resistance (Armstrong & Murphy, 2011). For example, men with erectile difficulties who take Viagra have been seen to challenge the dominant medical model of erectile dysfunction, one in which dysfunction is viewed as a pathology to be treated, and instead construct their difficulties within a discourse of normal ageing (Potts et al., 2004). In this way, behaviourally men are seen to engage with dominant medical discourses (i.e., by taking Viagra); however, conceptually, they resist the medical discourse by constituting their difficulties within an alternate and personally meaningfully discourse. Within my project, noting the nuances of resistance is important as it assists me to be critical of how women create space to engage or not engage with screening in ways that are meaningful to them. Being critical of how women are positioned to engage in screening, by themselves and others, is an important component of my endeavour to support informed choices within this context as it enables me to examine if a diversity of experiences (i.e., choices) is equally respected.

2.2.3.3 Governmentality

Governmentality refers to the techniques (i.e., technologies) and ways in which institutions of power (i.e., the State) try to produce citizens who fulfil institutional aims (Foucault, 1972). Within the concept of governmentality techniques refer to a set of changeable technologies and rationalities that are employed to obtain a common goal—“to lead the population to do what is considered best for the state and the population, but nevertheless leaving the individuals with a sense of making their own choices” (Solbjør, 2008, p. 29). Thus, governmentality is about disciplining and regulating the population’s health and wellbeing through indirect means (Flynn, 2002). In this thesis I do not aim to identify the specific techniques that governments employ in positioning women to engage in screening mammography. Nonetheless I discuss the concept of governmentality due to its prominence in the production of subject positions—an artefact my project aims to identify, and governmentality’s understanding of autonomy—as influenced by the socio-cultural, historical, and political environment.

Within the framework of governmentality, subject positions are made available through a complex interaction of technologies of power and technologies of the self (Foucault, 1984/1991). Technologies of power represent the ways in which disciplines (i.e., institutions of power such as law and medicine) succeed in making a population less dangerous, more productive, and politically docile (Foucault, 1977). For example, as described earlier, surveillance (by the institution of medicine) represents a technology of power that is able to constitute the body as an object, produce knowledge upon it, then categorise it either as normal or abnormal (Armstrong, 2004). Thus, through the medical gaze, the body is disciplined and encouraged to take action to return to normalcy (Armstrong, 2004). As such, a certain way of being or subject position for that individual is made available to “take-up”. In his later work, Foucault (1984/1991) developed the concept of technologies of the self to capture how individuals are able to resist the practices that attempt to dominant and discipline them. Technologies of the self refers to the ways in which individuals come to understand themselves as subjects (McNay, 1994). In this way, people are not passive in relation to dominant discourses and instead actively reproduce or resist the dominant discourses (Armstrong & Murphy, 2011). As such, arguably, the individual is seen to have autonomy and be able to constitute their own subjectivity (Armstrong & Murphy, 2011). However, the subjectivity and associated practices adopted by the individual are not "invented" by themselves—"they are models that he [sic] finds in his culture and that are proposed, suggested, imposed upon him by his culture, his society and his social group" (Foucault, 1984 p. 441). In other words, the ways of being made available to us are constructed by the socio-cultural, historical, and political environment that we are embedded within—although we do not have to adopt dominant ways of being, our choices are still limited as to what circulates in the environment. As such, to support women in making an informed choice within breast screening, it is imperative to first identify if the socio-cultural environment provides this opportunity—subject positions that permit informed choice.

2.2.4 Foucault and Feminism: How they inform this research

Foucault and feminism share several similarities that enable me to draw cohesively on both perspectives within this project. For example, Foucault's (1984/1991) recognition that the subjectivities individuals adopt are constituted by power relations around them, and feminist ideas that the socio-cultural, historical, and political environment is inescapable (Donchin, 1995; Ells, 2003), are notions that both oppose the construction of the discrete autonomous self that is privileged within the biomedical perspective of autonomy (Ells, 2003). Ultimately, of importance to my project, both recognise that autonomy is bound by options made available in the environment and power relations (Ells, 2003; Foucault, 1984;

Handa & Sharpe, 2015). Thus, both perspectives are keenly interested in identifying the social norms that serve to privilege certain options over others (Ells, 2003; Miner, 2017). Finally, Foucault and feminism both recognise that people are not free in the same way. For example, Foucault recognised how the prisoner may be able to change their attitude about their situation, however unable to act freely in any other way (Ells, 2003), while in contrast feminist-scholars more readily recognise that people's freedom can be constrained by demography (e.g., race, gender, sex, class, and religious affiliations; Ells, 2003).

Although there are differences between the perspectives—Foucault has been criticised for obscuring the extent to which regulatory processes are gendered (Allen, 2014; Howson, 1998). Feminists however recognise that the female body has been/is rendered more "docile" than the male body and that this has been due to disciplinary techniques and practices that have, and continue to, specifically target women (Allen, 2014). The lack of attention to gender within Foucault's work represents one of two reasons why, despite their similarities, I draw from both perspectives within this project. The other important reason pertains to the lack of a normative framework offered by Foucault's work (Ells, 2003). While Foucault provides a useful and important way to analyse power and associated subjectivities, he refrains from differentiating between "better and worse social practices grounded on different forms of power" (Ells, 2003, p. 218). However, feminist perspectives, who are attentive to forms of oppression and liberation, do differentiate between such social practices (Ells, 2003), and thus can provide a moral framework for my project.

As such, my project draws on both perspectives and regards them as complementary. Foucault's work assists me to formally identify the subject positions that are made available to women within the breast screening context, while feminist-theory facilitates my argument that women should be supported to make an informed choice within the breast screening context. Notably, both perspectives can be drawn upon to critique the biomedical perspective of autonomy; and thus argue for a reconceptualisation of autonomy and informed decision-making within policy and practice.

2.2.5 Foucauldian discourse analysis

FDA draws form Foucault's work on discourse and power/knowledge; ideas that have been important in shaping critical questionings of dominate understandings and taken for granted "truths" (Silcock, 2013). As such, a particular interest of FDA is exploring how truth is established and attained within discourses (Hook, 2007). In this line of exploration, a historical perspective is adopted to understand how modern-day discourses have come to be (Silcock, 2013). However, within my project I draw more strongly on versions of FDA that focus on exploring the consequences of using certain discourses—my analysis seeks to identify which discourses assume dominance and thus identify the social realities that are privileged over others (Willig, 2013). In this way, my use of FDA is entrenched in understanding how discourse may legitimatise certain ways of being and (re)produce power hierarchies (Willig, 2013). More specifically, my adaption of FDA focuses on identifying discursive resources that are available to women in the breast screening context, what subject positions they make available, and to critically question if subject positions offer opportunities to make an informed choice. Overall, a FDA of the discourses used by women, mass media, and GPs will provide insights into how power is operationalised through language in day-to-day contexts and whether it may act as autonomy supporting or undermining in the context of breast screening and choice.

Whilst there is no prescribed procedure for conducting a FDA (Given, 2008; Willig, 2013), my project adopted the six steps outlined by Willig (2013). Willig's (2013) process is appropriate to my project because of the attention given between discursive constructions and individual subjectivity/behaviour. The process is discussed in greater depth in Chapters 4, 5, and 6 (Study 2, 3, and 4), and as such, as are only briefly explained here. The process first focuses on identifying ways in which the discursive object under examination is constructed, followed by identifying how such constructions can be understood in wider discourses. Next, the process involves exploring what can be gained from constructing the discursive object in this way and identifying subject positions made possible. Finally, the process encourages consideration of what practices and experiences are made legitimate within the identified subject positions. While the steps are numbered, the process did not occur in a linear fashion, instead, the prescribed process acted as a roadmap that evolved throughout the analysis (Willig, 2013).

2.3 Ethical Considerations

The national statement on Ethical Conduct in Human Research (The National Health and Medical Research Council [NHMRC], 2015) and Code of Ethics (Australian Psychological Society, 2007) guided practice in this research project. As studies 2 and 4 (Chapters 4 and 6) required data collection from human participants, they were provided with a plain language information sheet outlining their role, foreseeable benefits and harms, data collection/storage procedures, confidentiality, and their right to withdraw (APS Statement a.3; see Appendix E and J). In recognising it would be unethical to provide medical advice, contact details of breast cancer organisations were included at the end of information sheets. In addition, participant reimbursements for time (i.e., coffee, parking, and a $120 department store gift cards), Myer gift card receipt forms, and consent forms (See Appendix F), were provided with the information sheet, signed by the participants and retuned prior to study commencement. To ensure confidentiality, participant information was de-identified after the transcription process. A professional transcription service was used to transcribe the audio-recordings and had access to any identifiable information stated by the participant during the interview. This made clear to participants via the information sheet, where they were also provided an opportunity to request the service’s privacy policy.

In accordance with NHMRC (2015) audio recordings, electronic transcripts and accompanying data files were stored in a password protected computer at Curtin University. Hard copies of consent forms, demographic details and transcripts were stored securely in a locked cabinet at a private desk at Curtin University. Consent forms and demographic sheets were stored separately in locked cabinets to ensure demographic details could be linked to names. Data will be kept in secure conditions for a minimum of 7 years after the completion of the study and then destroyed in accordance with Curtin University’s data storage policy.

Chapter 3: A Systematic Review of Women's Knowledge of Screening Mammography

3.1 Chapter Overview

In this chapter I present the first study conducted in the project, and the first published systematic review to examine women's knowledge of screening mammography. The review, titled "A systematic review of women's knowledge of breast cancer" (Seaman, Dzidic, Castell et al., 2018) is published in *The Breast*, an international and multidisciplinary journal disseminating research on the advancement of breast cancer prevention, diagnosis, and treatment knowledge. The published manuscript in this chapter synthesises 35 studies published from 1992 to 2017 which included original data on women's knowledge/understanding of screening mammography. The published manuscript concludes with the identification of topics both well and misunderstood by women and several recommendations for future research. The findings of the systematic review helped to generate a clearer understanding of the misconceptions held by women about screening, and for the thesis, contributed to our recommendations for improved communication of breast health.

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2018). A systematic review of women's knowledge of screening mammography. *The Breast, 42,* 81-93. https://https://doi.org/10.1016/j.breast.2018.08.102

3.2 Abstract

In light of the contention surrounding the benefit-to-harm ratio of screening mammography, this systematic review aimed to understand women's knowledge of screening mammography. The search yielded 35 studies of varying methodologies, published/completed between 1992 and 2017. Data was collected between November 2017 and February 2018 and utilised publications from member countries of the International Cancer Screening Network- Breast Cancer Division. Data was analysed using a narrative synthesis. The results of the review suggest that most women are aware of mammograms, however there was large variability regarding the awareness of false positives/negatives and about the purpose of screening. Some topics (e.g., radiation, commencement age) are well understood by women; however, others are not (e.g., cessation age, overdiagnosis, and mortality reduction). The findings need to be considered in light of the variability of methods used to assess women's knowledge and there is a need to develop psychometrically validated and culturally appropriate measures of knowledge regarding screening mammography. Further, the lack of consensus regarding what women 'should' know in order to provide informed consent has implications for understanding what informed consent in breast screening means in practice.

3.3 Introduction

Breast cancer is the most commonly diagnosed women's cancer worldwide (World Health Organisation, 2014). The International Cancer Screening Network (ICSN)-Breast Cancer Division is a consortium of 27 countries that have population-wide breast cancer screening programs. In these countries, there is a strong emphasis on population-based screening mammography targeting asymptomatic women with the aim of detecting breast cancer before it is otherwise identified (https://www.cancer.gov/about-nci/organization/cgh/research/icsn). Although screening mammography is the most accurate breast cancer detection method (Lauby-Secretan et al., 2015), there are concerns for the benefit-to-harm ratio it poses to asymptomatic women (Gøtzsche & Jørgensen, 2013). Potential benefits of screening mammography include; early diagnosis (Morris, Feig, Drexler, & Lehman, 2015), increased treatment options and less invasive treatment (Armstrong, Moye, Williams, Berlin, & Reynolds, 2007), opportunity for breast-conserving surgery and improved survival (The Australian Institute of Health and Welfare, 2015), and reassurance when the screen is negative (Griffiths, Bendelow, Green, & Palmer, 2010). The reduction in relative risk of breast cancer-specific mortality following mammography is often cited as 15-20% (Pace & Keating, 2014); however, benefit varies according to age (Mathieu et al., 2010; Nelson et al., 2016). For example, women aged 60-69 are most likely to benefit from reduced risk of breast cancer-specific mortality while women aged 40-49 are less likely to experience this reduction and more likely to experience false positive results and unnecessary biopsy (Siu, 2016).

However, these benefits should be considered against the potential harms from overdiagnosis, which are the detection of a tumour which would not have otherwise become clinically evident in the patient's lifetime (Pace & Keating, 2014), and subsequent over treatment, as well as false positives (i.e. abnormality seen on mammogram which turns out to be benign), unnecessary investigations, and false reassurance, as well as "screening anxiety". Estimates of overdiagnosis range between 0% and 50% (Marmot, Altman, & Cameron, 2013). Currently it is not always possible to distinguish between potentially fatal and harmless cancers (Jørgensen & Gøtzsche, 2009), meaning that many women undergo treatments such as radiation, surgery, and occasionally chemotherapy or hormone therapy that yield no individual survival benefit (Morris et al., 2015). Additionally, false positives, wherein a woman is re-called for further tests that later reveal she does not have breast cancer (Brodersen & Siersma, 2013), are associated with increased anxiety, breast cancer-specific anxiety, and perceived risk of breast cancer (Nelson et al., 2016; Salz, Richman, & Brewer, 2010; Tosteson et al., 2014). These psychological harms are compounded by the potential for harm from unnecessary (albeit very low dose) radiation posed by mammography. While no study has directly examined the relationship between mammography radiation and cancer incidence and death (Nelson et al., 2016), a modelling study suggested that, for women screened annually from the age of 40-55 and then biennially thereafter to age 74, radiation will induce 86 cancers and 11 deaths per 100, 000 women (Yaffe & Mainprize, 2011).

As a result of this controversy an independent review was commissioned in the UK led by an eminent epidemiologist Sir Michael Marmot. This identified 11 randomised trials examining the efficacy of mammography (Marmot et al., 2013). Considerable variation existed in the trials' randomisation processes, participant age groups, intervals between screens, time between follow-ups, number of screens, whether self-examination was also used, type of mammography, and system for classifying breast cancer deaths (Marmot et al., 2013). The review concluded that these biases were unlikely to distort results significantly and estimated a 20% reduction in breast cancer mortality (Marmot et al., 2013). Using the above figure, over 20 years, for 10,000 women aged 50 who are screened every 3 years, 681 cancers will be detected (129 likely from overdiagnosis), and 43 deaths prevented. The review also acknowledged harms such as increased anxiety, physical discomfort, and overdiagnosis.

Research demonstrates that many women hold inaccurate perceptions about the benefits/harms of screening mammography. In two studies, more than half of the sample estimated mortality reduction to be between 50% and 70%, a highly inflated figure (Chamot & Perneger, 2001; Domenighetti et al., 2003). Studies have shown that 45% of women falsely believed that screening mammography prevented cancer (Webster & Austoker, 2006), and 68% of women believed screening mammography prevented or reduced the risk of developing breast cancer (Domenighetti et al., 2003). In addition, misconceptions pertaining to age have been reported; 83% of women believed mammography had 'proven' benefit for women aged 40-49 years while 38% cited 'proven' benefit for women under 40, despite no such data existing at the time (Woloshin et al., 2000). Conversely, women tended to underestimate the harms of screening mammography (Hersch et al., 2015; Hersch et al., 2014; Waller, Douglas, Whitaker, & Wardle, 2013). For example, one study reported that 32% of the sample was unaware of false positives (Webster & Austoker, 2006) and another found that 8% of the sample was unaware of any potential harms to healthy women (Schwartz, Woloshin, Fowler Jr, & Welch, 2004).

These studies suggest that many women do not have an accurate understanding of the benefits/harms imposed from screening, which has implications for their ability to provide informed consent for participation based upon an accurate understanding of the consequences of participation (Hersch et al., 2011; Mathieu et al., 2010). The necessity for women to understand harms/benefits is heightened considering breast screening targets ‘healthy’ women as a population-wide primary prevention strategy. The development of decision aids has shown an increase in the number of women making an informed decision prior to screening participation (see Mathieu et al., 2007; Mathieu et al., 2010; Smith et al., 2010). However, to make best efforts towards the uptake of informed decision-making, we must first understand what women know about screening. Thus, this research aims to be the first study to systematically review the literature on women’s knowledge of screening mammography from participating countries of the ICSN– Breast Cancer Division.

3.4 Methods

Between November 2017 and February 2018, we systematically searched the literature for studies of women’s knowledge of screening mammography. The search strategy, data sources, inclusion/exclusion criteria, data extraction process, risk of bias assessment, and analysis strategy were specified *a priori* and registered with the International Prospective Register of Systematic Reviews (registration number CRD42016045225). The review is structured according to The Preferred Reporting Items for Systematic Reviews and

Meta-analysis (PRISMA) guidelines (Moher et al., 2015). The review was approved by Curtin University Human Research Ethics Committee.

3.4.1 Inclusion and Exclusion Criteria

Studies were considered if they reported original data (quantitative, qualitative, and mixed) on women's knowledge/understanding/awareness of screening mammograms and were published in, or translated to, English. Intervention studies (where pre/post knowledge was collected) and responses to policy changes or knowledge of recommended guidelines were included. For intervention studies, only pre-intervention knowledge was included. Additionally, studies had to report data from countries that are members of the ICSN– Breast Cancer Division and had/have a national mammography screening program at the time of data collection. Furthermore, participants were women 40 years or older; the age at which screening recommendations for women begin (World Health Organisation, 2014). Where this was ambiguous, the percentage of women over the age of 40 within the sample had to be 50% or more or the mean age be 50 years or above. Studies were excluded if women were recruited based on current or past diagnosis of breast cancer.

3.4.2 Search Strategy

Databases (PubMed, All Journals@Ovid-Abstracts and Full Text, Scopus, PsycINFO, Google Scholar, and ProQuest Central) were electronically searched, followed by a subject-specific database, EPPI-Centre-TRoPHI, and grey literature (ProQuest Dissertations and Theses Database, The National Institute for Health Care Excellence, and Open Grey). Search terms were women* OR woman* AND knowledge OR awareness OR understanding OR attitude OR perception OR view AND mammogra* OR "screening mammogra*" OR "breast screening mammogra*" OR "breast cancer screening." Truncation and search limits such as human and/or female were activated where possible. Search alerts were created for all databases to retrieve articles published after cessation of initial data searching. Journals yielding the greatest number of articles were manually searched. Reference list and citation searches were also conducted on a random sample of 10 papers (Moher et al., 2015). An expert oncologist/breast cancer specialist helped to identify additional papers and databases.

3.4.3 Quality Assessment

Each study was scored against the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet, Lee, & Cook, 2004). Quality was classified as follows; limited (less than .50), adequate (.50-.70), good (.70-.80), or strong (greater than .80; Lee, Packer, Tang & Girdler, 2008). A random 10% of studies *(n* = 4) was assessed for quality by two independent reviewers, leading to a Cohen’s Kappa of .77. Discussions amid reviewers then occurred to reach consensus. The remaining articles were then assessed for quality by the first author. One study was excluded due to poor quality.

3.4.4 Analysis

Due to heterogeneity in knowledge measurements, designs, and samples, a narrative synthesis was employed. The synthesis was informed by the Guidance on the Conduct of Narrative Synthesis in Systematic Reviews (Popay et al., 2006) to develop an initial description of studies, explore relationships within and between studies, and assess the methodological rigour of included studies and the robustness of the synthesis. The results of each study were interpreted according to guidelines about mammography screening for breast cancer at that time and within that location to allow for an examination of temporal changes in women’s knowledge.

3.5 Results

3.5.1 Study Characteristics

Database searching yielded a total of 13,955 articles. Hand searching yielded an additional 31 articles. After deleting duplicates, 10,542 articles remained. Title/abstract screening resulted in the exclusion of 10,428 articles. A total of 114 articles satisfied criteria and no new studies were identified from reference list and citation searches, or expert consultation. Full-texts of the 114 articles were assessed for eligibility, 35 of which (published/completed between 1992 and 2017) satisfied all inclusion/exclusion criteria (34 journal articles and 1 unpublished dissertation; see Figure 3).

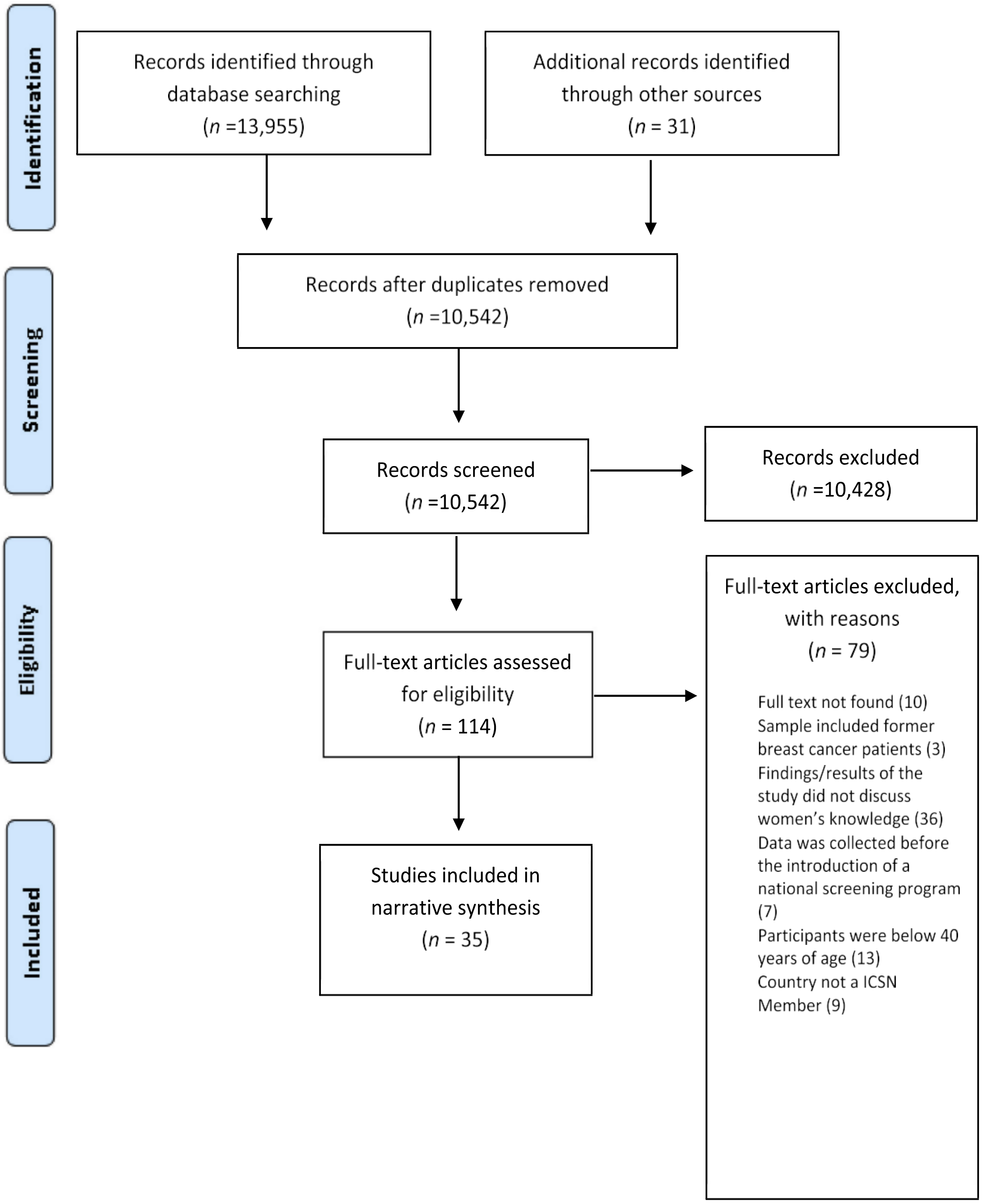

Figure. 3. *PRISMA flow chart of study selection and results*.

Of the 35 included studies (Table 1), 26 were quantitative, and nine were qualitative. Twenty-one quantitative studies employed a cross-sectional design, four used a randomised control trial design, and the remaining study used a quasi-experimental design. To collect data, varying methods of survey were utilised; telephone (*n* =10), face-to-face (*n* = 8), mail (*n*

= 5) and web-based (*n* = 3). Qualitative studies predominately utilised focus groups (*n* = 6) followed by one-on-one interviews (*n* = 3). Studies were most commonly conducted in Australia (*n* = 11), followed by the UK (*n* = 7), Germany (*n* = 5), and Spain (*n* = 3), with one to two studies from each remaining country (Table 1). There were no studies from 11 of the 27 ICSN countries.

3.5.2 Quality Appraisal

The mean quality appraisal score was .84 (*SD* = .07, range = .75-1) for the qualitative studies and .83 (*SD* = .09 range = .55-1) for the quantitative studies.

3.5.2.1 Participant selection. The range of sampling strategies used—convenience (*n* = 9), snowball (*n* = 2), purposive (*n* = 5), random (*n* = 9), random stratified (*n* = 7), and random digit dialling (*n* = 3)—may have introduced bias. An analysis of generalisability revealed, of the studies aiming to sample the wider community (*n* = 26), ten achieved a representative sample, and 16 failed due to one or more reasons related to recruitment—accessing a sample who may be more health conscious (*n* = 5), telephone only recruitment (*n* = 5), drop-out bias (*n* = 1), online recruitment only (*n* = 1) and over/under sampling a characteristic (*n* = 8). The remaining nine studies aimed to sample a specific population. Authors of two studies reported achieving a wide variety regarding age, education, and experience with mammography within their sample, while authors of another four studies noted their samples were not representative of their intended population due to bias associated with their sample being overly health conscious (*n* = 1) and overrepresentations of certain characteristics (*n* = 3). The remaining three studies provided no commentary. Seventeen studies provided data on response rates, which ranged from 16.3% to 85%. Women’s age ranged from 18 to 75+ years; however, 18 studies reported all of their sample as over 40, while the remaining ranged from 54% to 68%.

3.4.2.2 Confounding bias. Positive correlations between screening mammography knowledge and previous experience with screening, education, marital status, and work status have been reported in the literature (Al-Dubai et al., 2011; King, Balshem, Ross, Seay &, Rimer; Sim, Seah & Tan, 2009). As such, it is important to note some studies included an overrepresentation of women described as; tertiary educated (Berens, Yilmaz-Aslan, Spallek, & Razum, 2016; Cockburn, Pit & Redman, 1999; Hippman et al., 2015; Mathieu et al., 2010), having prior mammogram experience, having little to no primary schooling (Soskolne, Marie, & Manor, 2007) and as married and working (Cockburn et al, 1999).

3.4.2.3 Power to detect effects/data saturation. Sample sizes for quantitative studies ranged from 41 to 4,648 women. For studies reporting socio-demographic associations with knowledge (n = 11), only two studies reported conducting *a priori* power analyses (Table 1). As such, confidence in interpretation may be compromised by insufficient sample sizes. Sample sizes for qualitative studies ranged from 6 to 78 women. Three studies (33.33%) reported employing data saturation as an indication of data robustness (Banning, 2011; Ferrat et al., 2013; Hersch et al., 2013); while the remaining six did not mention data adequacy/quality assurance (see Table 1).

3.4.2.4 Study heterogeneity. Of the quantitative studies, the majority (n = 19) used surveys developed by the authors, three used adapted questionnaires, and four used pre-validated surveys. In developing the surveys, seven were informed by prior literature, followed by collaborative efforts with health experts (n = 2) and with women (n = 1). For nine surveys, the development phase was not reported. Eight studies verified their survey instrument via pilot studies and none provided psychometric properties.

Studies' contribution to an understanding of what women know about screening mammography varied. For example, six studies (see Table 2) provided a collated 'knowledge score', which precludes the identification of specific areas of understanding or confusion in women's understanding (i.e., screening topics women answered incorrectly). Furthermore, the varied response options offered to women limits interpretation (see Table 2). In the 26 studies that used multiple-choice questions, the number of response options ranged from two (e.g., true or false) to eight; fewer options represent a better chance of women 'guessing' correctly, which may have skewed the data and strategies to minimise this bias was not discussed. For the qualitative studies, data collection materials were informed by literature (*n* = 3) or aided by health experts and women (*n* = 2), or development processes were not specified.

3.5.3 Synthesis of Findings

Findings were synthesised according to the specific areas of knowledge of mammography examined in the studies (Table 2). To aid readability, we often report the researcher-determined 'correct' responses; these are contextualised within the time and place of each study to assist with identifying any patterns.

3.5.3.1 Awareness of screening mammography. Nine studies examined women's awareness of screening mammography, which ranged from 47.2% to 99.9% (see Table 2). Higher levels of awareness were associated with women aged 50-69 years and post-secondary school qualifications (Barratt, Cockburn, Redman, Paul, & Perkins, 1997).

3.5.3.2 Purpose of screening mammography. Six studies examined women's perceptions of the purpose of screening mammography; however, the purpose of screening mammography, which was defined by the authors, differed between studies. Four studies considered cancer detection as the 'most correct' answer; the percentage of women who selected this response ranged from 20% to 98%. One study considered early detection of breast cancer as the purpose of screening with 49.6% of women responding correctly (Van

Agt Heleen, Fracheboud, van der Steen, & de Koning, 2012). Finally, Domenighetti et al. (2003), discussed the purpose in terms of risk-reduction of breast cancer; 26% of women correctly answered that breast screening does not have any influence on risk of breast cancer, while 47% believed it reduced the risk of breast cancer, 21% thought screening prevents the risk of developing breast cancer, and the remaining were unsure. Mah and Bryant (1992) reported women 60 years and over were less likely than women below 60 to believe that mammography could detect new breast cancer.

3.5.3.3 Knowledge of recommended guidelines. In 12 studies, women were asked the age and/or frequency with which women should attend screening mammography. Six studies directly asked women the age screening mammography should begin with the percentage responding ‘correctly’ ranging from 7% to 60.3%. In two studies (Achat Close, & Taylor, 2005; Villanueva et al., 2008), the majority of women (67% and 56.8%) stated screening began at an age younger than their countries recommended age. Data was unclear in four studies to undergo further analysis. In considering screening cessation ages, the studies (*n* = 3) showed that the majority of women believed that there is no recommended age for screening cessation, with only 12.7%, 15.3% and 24.7% stating the correct age range to cease screening.

Ten studies examined women’s ability to identify the recommended frequency of screening. The percentage of women offering a ‘correct’ response ranged from 0% to 74%. In four studies, the second most selected option represented an underestimation of frequency (Achat et al., 2005; Barratt et al., 1997; Chamot, Charvet, & Perneger, 2007; Villanueva et al., 2008). Women defined as ‘ever-attenders’ (attended at least one screening) were more likely to know the recommended frequency than ‘never-attenders’, but ‘never-attenders’ were more likely to know the correct recommended age to begin screening (Achat et al., 2005).

3.5.3.4 Harms of screening mammography. In two studies, the potential for screening to 'fail' detecting cancers was discussed by non-attenders of screening (Ferrat et al., 2013; Lagerlund, Widmark, Lambe, & Tishelman, 2001). Figures of awareness for false results varied, with awareness of false positives ranging from 46.3% to 98% and awareness of false negatives ranging from 10% to 90%. Only 2% of women noted the potential for false results (Cockburn et a., 1999) and approximately a quarter of each sample in Baena-Cañada et al. (2014), Barratt et al. (1999) and Cockburn, Hill, Redman, and Henry (1995) selected the correct mammography sensitivity figure.

Overdiagnosis was examined in 12 studies. Awareness of overdiagnosis ranged from 29.27% to 72.4 %, with four studies reporting figures below 50%. One study (Baena-Canada et al., 2014) reported that women overestimated the occurrence of overdiagnosis; similar information was not available in other studies. While women in one study acknowledged screening was not infallible (Ferrat et al., 2013), the remaining eight studies revealed women were unaware of overdiagnosis, surprised by it, and had difficulty grasping the concept (Hersch et al., 2013; Henriksen, Guassora, & Brodersen, 2015; Lagerlund et al., 2001; Sommer et al., 2016; Waller et al., 2013).

Five studies suggest women perceived minimal harm from radiation in screening mammography. The percentage of women expressing concern is below 20% (Cockburn et al., 1999; Lagerlund et al., 2000) while a minority of women in the remaining studies discussed this concern—several women in Ferrat et al. (2013), two out of eight focus groups in Lagerlund et al. (2001) and one woman in Kissal (2011).

3.5.3.5 Mortality reduction efficacy. Seven studies reported women's perceptions of the mortality reduction generated from participating in mammograms. A minority of women (0.85% to 24%) indicated correct estimates and 45.6% to 82.6% of women across seven countries overestimated the mortality reduction from mammograms. The remaining studies assessed women's perceptions of efficacy more broadly—43.3% of women agreed that fewer women die from breast cancer thanks to screening (van Agt Heleen et al., 2012), 75.9% of attenders and 48.2% of non-attenders agree mammograms can find cancer up to two years before symptoms and 94.1% of women agreed breast cancer could be cured with early detection from mammograms (Luengo-Matos, Polo-Santos, & Saz-Parkinson, 2006). Methods of assessing mortality reduction efficacy differed substantially between studies; however, all indicate the majority of women overestimate the mortality reduction from screening.

3.5.3.5 Perceived necessity of screening mammography. Nine studies elicited women's perceptions of the necessity of undergoing screening mammography. The majority (94.5%) of women in one study considered mammography as necessary (Villanueva et al., 2008) and 96.9% of women in another believed participation to be compulsory (van Agt Heleen et al., 2012). The majority of women (88% to 97%) in four studies correctly identified that screening was for non-symptomatic women while much lower percentages (1.3% and 1%) were reported in two studies (Barratt et al., 1977; Cockburn et al., 1999). Finally, four out of five focus groups with non-attenders (Lagerlund et al., 2001) and 100% of attenders and 96.2% of non-attenders considered future screening unnecessary upon the receipt of negative results (Chouliara, Power, Swanson, & Johnstone, 2002).

Screening mammography programs were perceived as useful, lifesaving, the best way to detect cancer, and more beneficial than harmful (Cockburn et al., 1999; Ferrat et al., 2013; van Agt Heleen et al., 2012; Villanueva et al., 2008). Women felt reassured by attending a screening (Lagerlund et al., 2001), even after being presented with information regarding the potential for overdiagnosis (Hersch et al., 2013). Less favourable views were also expressed;

attenders perceived screening as uncomfortable while non-attenders regarded the procedure as aggressive, painful, and disrespectful (Ferrat et al., 2013). Furthermore, some women (non-attending) stated screening does not save lives (Lagerlund et al., 2001) and a few women believed mammography was harmful to breasts and could cause cancer (Kissal, 2011).

3.5.3.6 Knowledge score. Seven studies produced a score related solely to women's knowledge of screening mammography and four studies produced scores that examined knowledge on screening mammography and breast cancer. The scores of these studies should be interpreted cautiously as we were unable to differentiate women's understanding of screening versus breast cancer. The topics covered by each questionnaire can be seen in Table 2.

Ten studies reported their sample's mean and standard deviation, one study reported the percentage of women considered 'adequately' informed, and six provided both. In all studies, 'sufficient' knowledge was a score equating to more than the mid-point of the range. In seven studies, the group mean indicated that women were not 'sufficiently' knowledgeable. In the six studies reporting frequencies, one to 83% of women were 'adequately' knowledgeable; however, the majority of studies (n = 4) reported figures below 50%.

Six studies reported associations with increased knowledge; these were women who were considered to have a higher education (Baena-Cañada et al., 2014; Berens et al., 2015; Cockburn et al., 1995; Domenighetti et al., 2003), defined as non-immigrant women (Berens et al., 2015), were attenders of screening (Lagerlund et al., 2000), employed, unemployed, or retired compared to women defined as homemakers (Baena-Cañada et al., 2014) and those aged 50-59 compared to under 50 (Gigerenzer, Mata, & Frank, 2009).

3.6 Discussion

The aim of this study was to understand women's knowledge of screening mammography to inform strategies to improve communication and informed consent. The results suggest that most women are aware of mammograms; however, the remaining areas of knowledge exhibit more variability. Regarding knowledge of screening guidelines, up to 66% of women were aware of the age to commence and the frequency with which to attend screening. Knowledge of the age to cease screening was low. There was a wide range in accurate understanding of the purpose of screening and awareness of the possibility false positives/negatives. Few women accurately understood the sensitivity of mammograms, with both over and underestimates reported. Furthermore, greatest confusion was found in understanding concerning overdiagnosis and mortality efficacy. In most studies, fewer than 50% of women were aware of overdiagnosis and often reported confusion when presented with the concept. A minority of women accurately understood the life-saving benefits screening offers participants but the majority significantly over-estimated this figure. The confusion associated with overdiagnosis, and over-estimations of mortality efficacy, are common (Chamot & Perneger, 2001; Nekhlyundov et al., 2008). Some suggest this may be a result of positively-biased information accessible to women (Hersch et al., 2011; Jørgensen & Gøtzsche, 2004). However, there were two topics where women's understanding aligned with research findings—that the harm from radiation is likely to be low and that screening is only indicated for asymptomatic women (Amoran, Toyobo, & Fatugase, 2014; Peppercorn et al., 2015). Finally, we analysed data on collated knowledge scores; most studies reported the majority of their sample as 'insufficiently' knowledgeable. For the four studies reporting the majority of their sample as 'adequately' knowledgeable, their surveys neglected questions associated with overdiagnosis and mortality efficacy, which may have led to an inflated score.

We considered how temporal changes and societal trends/publication of influential research could explain patterns of responding. Regarding the influence of program ‘age’ at the time of data collection, barring one topic (women from programs in their infancy accurately understood the purpose more often), there appeared to be no clear pattern. Women’s higher awareness of the target group of screening (asymptomatic women), could be explained by campaigns that convey the message that early detection saves lives. Such campaigns were prominent in the mid-70s to mid-90s and established a trend that suggests screening is a ‘check’ for healthy women and that it saves lives (McNair Ingenuity Research Group, 2015). We speculate such campaigns may contribute to women’s overestimation of mortality reduction offered by engaging in screening and belief that screening does not have a recommended cessation age. However, we also note this figure has been highly debated in the research literature, ranging from 15% to 30% (Pace & Keating, 2014; Shapiro et al., 1985), which may cause confusion to women. The incidence of overdiagnosis is another debated subject in the screening literature; however, some research from the late 2000s concludes that one in three breast cancers are overdiagnosed (Bleyer & Welch, 2012; Jørgensen & Gøtzsche, 2009). This conclusion is still heavily debated and may help to explain why media campaigns omit information about overdiagnosis (Hersch et al., 2011; Jørgensen & Gøtzsche, 2004) and why women still report low levels of awareness of overdiagnosis. As such, the review provides a commentary about health promotion over time and creates a historical log of informed consent, which may be useful in identifying societal factors that supported or impeded informed consent.

The findings need to be considered in light of the variability of methods that have been used to assess women’s knowledge. First, the lack of standardised measures of screening knowledge, as well as the use of non-validated researcher-derived measures, impedes accuracy. Second, there was limited detail about the design of 9 of 19 surveys and four of nine interview schedules. Third, there was considerable variability in what it meant to be an ‘informed’ participant of screening mammography. While the point at which women were deemed informed (a score equating to or more than the middle point of the range), was the same, the topics within each survey, and thus the ‘knowledge’ women were ‘expected’ to know, differed substantially. Given the lack of consensus regarding what women ‘should’ know in order to provide informed consent, we join a growing body of researchers who question the applicability of a universal definition of informed consent (Ghanouni, Renzi, Meisel, & Waller, 2016; Østerlie et al., 2008).

The strengths of this review lie in the methodological rigour imposed; the publication of a PROSPERO systematic review protocol facilitated transparency of process and peer review of methods. Processes of study eligibility, quality appraisal, and data extraction were conducted in collaboration with an independent reviewer, a standardised quality appraisal form, and a pre-piloted data extraction form was used. However, the standardised quality appraisal form includes only one question related to measures, which might explain why the studies scored highly on ‘quality’, despite the problems with their knowledge measures. Additionally, although efforts were made to reduce study heterogeneity (e.g. sample age, ICSN countries), the heterogeneity in ‘knowledge’ measures made synthesis of the literature difficult. Furthermore, we did not identify any study requiring translation to English, it is possible that some non-English language articles may have been overlooked.

There is a need to develop psychometrically validated and culturally appropriate measures of knowledge regarding screening mammography. The variability in the way knowledge was measured limits our understandings of what it means to provide informed consent. We suggest collaborative engagement with women and relevant health professionals may be of use in understanding what informed consent in breast screening means in practice. An examination of the social processes that may inhibit uptake of ‘new’ screening information would also be useful. Recent research, informed by bioethics, highlights how societal pressures contribute to enthusiasm for cancer screening, how screening has been constructed as ‘the right thing to do’, and how the normalisation of this construction may inhibit some women in engaging with updated information that outlines benefits/harms (Lau & Jaye, 2009; Seaman, Dzidic, Castell et al., 2018). There is also the opportunity to extend prior research that used content analysis of the information presented to women (Jones, 2004; Jørgensen & Gøtzsche, 2006). Critical analysis of the print and verbal discourse may offer an avenue through which to understand how women are positioned to engage with screening (e.g., a responsible woman engages in screening). Such positioning may impact negatively on opportunities to construct screening in accurate light; a practice that incurs benefit and harm.

In conclusion, the findings indicate women tend to overestimate the benefit of screening and underestimate the harm, which poses implications to ethics such as informed consent. Furthermore, the lack of standardised measures of screening knowledge and consensus on what women should know, positions us to join research which questions a universal definition of informed consent in the breast screening context.

Table 1: Summary of included studies systematically searched between November 2017 and February 2018

Author(s)/year/country	**Study Design**	**Sample**	**Knowledge Measurement**	**Quality Appraisal**
Achat et al. (2005) *Australia*	Cross-sectional survey	*N*=2974 Random sampling	Developed a survey Piloted with 50 participants	.89
Baena-Canada et al. (2014) *Spain*	Cross-sectional survey	*N*=434 Convenience sampling	Adapted a survey from a previous questionnaire by School of Public Health, Sydney, Australia	.80
Banning (2011) *Britain*	Exploratory descriptive Individual one-on-one interviews	*N*=10 Snowball sampling	Developed interview guide from previous literature	0.85
Barratt et al. (1999) *Australia*	Cross-sectional survey	*N*=115 Random sampling	Developed a survey Piloted with 20 participants, revised and again piloted with 100 participants	1
Barratt et al. (1997) *Australia*	Cross-sectional survey	*N*=2935 Random stratified sampling by states/territories and urban/rural	Developed a survey Piloted with 100 participants	.83
Berens et al. (2015) *Germany*	Cross-sectional survey	*N*=4113 Random sampling	Developed survey from previous literature	0.90
Berens et al. (2016) *Germany*	Exploratory descriptive Individual one-on-one interviews	*N*=10 Snowball sampling	Developed interview guide in conjunction with five health professionals	0.80
Chamot et al. (2007) *Switzerland*	Cross-sectional survey	*N*=932 Convenience sampling	Developed a survey	0.71

Chouliara et al. (2002) *Scotland*	Cross-sectional survey	N=59 Stratified random sampling by age and education	Developed a survey informed by the Breast Screening Programme leaflets/booklets	.85
Cockburn et al. (1995) *Australia*	Cross-sectional survey	N=405 Stratified randomly sampling by state and age	Developed a survey	0.55
Cockburn et al. (1999) *Australia*	Cross-sectional survey	N=200 Random digit dialling	Developed a survey	.75
Domenighetti et al. (2003) *UK, Italy, and Switzerland*	Cross-sectional survey	N=3137 Random digit dialling	Developed survey in conjunction with health experts and piloted with 82 women	.91
Ferrat et al. (2013) *France*	Exploratory descriptive Focus groups	N=34 Convenience sampling	Developed interview guide in conjunction with experts	1
Gigerenzer et al. (2009) *France, Germany, Italy, Spain, The UK, The Netherlands*	Cross-sectional survey	N=4658 Stratified random sampling by region, sex, size of household, profession and age	Developed a survey	0.86
Ham (2006) *Korea*	Cross-sectional survey	N=310 Convenience sampling	Developed survey from previous literature Reviewed by a four health experts	0.83
Henriksen et al. (2015) *Denmark*	Exploratory descriptive Individual one-on-one interviews	N=6 Purposive sampling	Developed interview guide from previous literature	0.80
Hersch et al. (2013) *Australia*	Exploratory descriptive Focus groups	N=50 Purpose sampling	Developed interview guide from previous literature Piloted with women	.90
Hersch et al. (2015) *Australia*	Randomised control trial	N=419, control group only Random sampling	Developed a survey from previous literature	0.92

Hippman et al. (2015) *Canada*	Cross-sectional survey	*N*=98 Convenience sampling	Used a pre-validated survey from prior literature	0.88
Kissal (2011) *Turkey*	Exploratory descriptive Focus groups	*N*=46 Purposive sampling	Developed interview guide Reviewed by seven health experts	0.75
Kwok & Lim (2015) *Australia*	Quasi-experimental survey	*N*=242 Convenience sampling	Survey adapted from the Chinese Breast Cancer Screening Beliefs Validated as reliable in previous literature	0.68
Lagerlund et al. (2000) *Sweden*	Cross-sectional survey	*N*=949 Stratified random sampling by mammogram attendance	Developed survey informed by unstructured interviews with 10 women Piloted with 40 women	0.80
Lagerlund et al. (2001) *Sweden*	Exploratory descriptive Focus groups	*N*=31 Random sampling	Developed an interview guide	.80
Mah & Bryant (1992) *Canada*	Cross-sectional survey	*N*=1284 Stratified random sampling by age	Survey was adapted from a pretested, standardized breast cancer and mammography questionnaire	0.73
Luengo-Matos et al. (2006) *Spain*	Cross-sectional survey	*N*=2409 Stratified random sampling by towns	Developed a survey	0.95
Mathieu et al. (2007) *Australia*	Randomised control trial	*N*=710 Random sampling	Developed a survey Piloted with 70 women	0.82
Mathieu et al. (2010) *Australia*	Randomised control trial	*N*=321 Convenience sampling	Used survey from Mathieu et al. (2007)	0.86
Nembhard & Trudy-Ann (2015)	Cross-sectional survey	*N*=41 Purposive sampling	Adapted survey from Champion Health Belief Model	0.86

UK			Scales Piloted with five women	
Reder & Kolip (2017) *Germany*	Randomised control trial	N=1052 Random sampling	Developed survey from previous literature	0.86
Sommer et al (2016) *Germany*	Exploratory descriptive Focus groups	N=40 Convenience sampling	Developed a interview guide	0.85
Sosklone et al (2007) *Israel*	Cross-sectional survey	N=510 Random sampling	Developed a survey from previous literature	0.91
Van Agt Heleen et al. (2012) *Netherlands*	Cross-sectional survey	N= 229 Convenience sampling	Developed a survey in conjunction with a health expert	.83
Villanueva et al. (2008) *Australia*	Cross-sectional survey	N=2995 Stratified random sampling by state/territory and urban/rural	Retained questions from 1996 Breast Health Survey as much as possible	.86
Waller et al. (2013) *UK*	Exploratory descriptive Focus groups	N=40 Purposive sampling	Developed interview guide	0.80
Waller et al. (2014) *UK*	Cross-sectional survey	N=2272 Stratified random sampling by age and location	Developed a survey from previous literature	0.75

Table 2. Summary of studies examining knowledge of mammography screening systematically searched November 2017 and February 2018

Concepts and Studies	Key Findings	Response Option	Program Age (years)	Notes
Awareness (*N* = 9)	**% Aware**			
Van Agt Heleen et al. (2012)	47.2%	Multiple choice – True, false, unsure	23	
Cockburn et al. (1999)	55%	Open response	8	
Banning (2011)	60%	Semi-structured interview	23	
Barratt et al. (1997)	63.2%	Open response	6	Higher levels of awareness associated with older age (50-69) and post-secondary school qualifications
Kwok & Lim (2015)	69.4%	Multiple choice – Yes, no, unsure	24	
Mah & Bryant (1992)	93%	Unclear	4	
Achat et al. (2005)	99.8%	Unclear	14	
Berens et al. (2015)	"Almost all had some idea about mammography"	Semi-structured interview	10	
Purpose (*N* = 6)	% Correct Response			
Cancer detection (*N* = 4)				
Banning (2011)	20%	Semi-structured interview	23	
Villanueva et al. (2008)	29.1%	Unclear	17	Correct responses associated with increasing age and prior mammogram.
Lagerlund et al. (2000)	25.4%[a] 67%[b]	Multiple choice- 2 answers	14	Correct responses associated with women described as Caucasian and college educated.

Mah & Bryant (1992)	93%^{c} 97%^{d} 98%^{e}	Unclear	4	Correct responses associated with being under 60 years.
Early detection ($N = 1$)				
Van Agt Heleen et al. (2012)	49.6%	Multiple choice - True, false, unsure	23	
Prevention ($N = 1$)				
Domenighetti et al. (2003)	26% (total sample)	Multiple choice – four answers	UK 15, Italy, 1, Switzerland 4	
Knowledge of Guidelines ($N = 12$)	% Correct Response			
Commencement age ($N = 6$)				
Mah & Bryant (1992)	7%^{e} 12%^{d} 23%^{c}	Unclear	4	
Achat et al. (2005)	20.5%	Multiple choice – 5 answers	14	Correct response associated with ‘never-attenders’ over ‘ever-attenders’
Villanueva et al. (2008)	41.1%	Multiple choice – 5 answers	17	
Kwok & Lim (2015)	41.7%	Unclear	24	
Barratt et al. (1997)	60.3%	Multiple choice – 5 answers	6	
Ferrat et al. (2013)	“Many” women new screening should be performed for women over 50^{f}	Organic conversation	24	
Cessation Age ($N = 3$)				
Barratt et al. (1997)	12.7%	Multiple choice – 6 answers	6	55.5% of participants believe there is no recommended cessation age.

Achat et al. (2005)	15.3%	Multiple choice – 5 answers	14	59.9% of participants believe there is no recommended cessation age.
Villanueva et al. (2008)	24.7%	Multiple choice – 8 answers	17	61.4% of participants believe there is no recommended cessation age.
Frequency ($N = 10$)				
Kissal (2011)	0%	Semi-structured focus groups	2	
Mah & Bryant (1992)	35%[g] 38% [c] 39%[e] 40%[d]	Unclear	4	
Lagerlund et al. (2000)	31.8%[a] 59%[b]	Unclear	14	
Barratt et al. (1997)	58.7%	Multiple choice – 5 answers	26	
Chamot et al. (2007)	69.1%	Multiple choice – 5 answers	8	
Villanueva et al. (2008)	71.2%	Multiple choice -7 answers	17	
Achat et al (2005)	74%	Multiple choice – 5 answers	14	Correct response associated with ‘ever-attenders- over ‘never-attenders’
Ferrat et al. (2013)	“Most” participants correctly cited biennial	Organic conversation	24	
Banning (2011)	Estimated yearly to five yearly	Semi-structured interview	29	
Berens et al. (2016)	Estimated 2 to 3 years	Semi-structured interview	11	
Harms ($N = 15$)	% Aware			

False results (unspecified) ($N = 4$)					
Ferrat et al. (2013)		Organic conversation	24		Discussions arose in non-participating[i] and non-attending women[j]
Lagerlund et al. (2001)		Organic conversation	15		Discussions arose in non-participating[i] women
Cockburn et al. (1999)	2%	Unclear	8		
False Negatives ($N = 2$)					
Lagerlund et al. (2000)	10%[b] 22.5%[a]	Multiple choice – agree, disagree	14		
Van Agt Heleen et al. (2012)	35.7%	Multiple choice- True, false, unsure	23		
Hersch et al. (2015)	90%	Multiple choice- yes, no	24		
False Positives ($N = 4$)					
Van Agt Heleen et al. (2012)	46.3%	Multiple choice- True, false, unsure	23		
Chouliara et al. (2002)	69%[b] 72.4%[a]	Multiple choice – Agree, disagree, unsure	14		
Baena-Canada et al. (2014)	88%	Multiple choice – Yes, no, unsure	19		Women believed for every 2000 women screened biennially over a 10 year period, 414 will experience false-positives, an overestimation of the statistically estimated 200.
Hersch et al. (2015)	98%	Multiple choice – yes, no	24		
Mammography Sensitivity ($N = 3$)					

Baena-Canada et al. (2014)		Open response	19	24% of women believed screening could detect 100% of breast cancers, 40.8% thought this figure was incorrect, 35% were unsure.
Barratt et al. (1999)		Multiple choice – 7 answers	8	24.8% of participants stated correctly selected mammograms sensitivity, while 41.7% underestimated, 32.2% overestimated and 6.1% were unsure.
Cockburn et al. (1995)		Multiple choice – 7 answers	4	26% of participants stated correctly selected mammograms sensitivity, while 18% underestimated, 35% overestimated and 11% were unsure
Overdiagnosis (*N* = 12)				
Nembhard (2015)	29.27%	Unclear	28	68.29% of participants said they learnt about overdiagnosis for the first time in the study
Baena-Canada et al. (2014)	31.3%	Multiple choice – Yes, no, unsure & probability estimate	19	Women believed for every 2000 women screened annually over 10 years, 177 women will undergo unnecessary treatment due to overdiagnosis; the statistical estimate is 10 women.
Hersch et al. (2015)	33%	Multiple choice – true, false	24	12% of participants knew the difference between over detection and false positive

Van Agt Heleen et al. (2012)	33.3%	Multiple choice- True, false, unsure	23	
Waller et al. (2014)	53%	Unclear	26	57% of participants demonstrated objective understanding after the study
Chouliara et al. (2002)	69%[b] , 72.4%[a]	Multiple choice- agree, disagree, unsure	14	
Lagerlund et al. (2001)		Organic conversation	15	Non-attenders acknowledged that mammography might incorrectly diagnosis some women
Hersch et al. (2013)		Guided discussions about overdiagnosis	22	Women were unaware of overdiagnosis and had difficulty grasping the concept
Henriksen et al. (2015)		Semi-structured interview	24	Participants were challenged by overdiagnosis information and asked for clarification
Ferrat et al. (2013)		Organic conversation	24	Women acknowledged screening is not infallible; opportunistic screening women (individually prescribed mammograms) held more positive attitudes towards overdiagnosis compared to non-opportunistic (non-attending) women.
Sommer et al. (2016)		Guided discussions about overdiagnosis	11	45% of participants were surprised and confused by overdiagnosis information

Waller et al. (2013)		Guided discussions about overdiagnosis	25	Overdiagnosis was mentioned in 4/6 of groups; however, only all women in one group were familiar with the concept.
Radiation ($N = 5$)	% Concerned			
Lagerlund et al. (2000)	5.4%[b] 20.5%[a]	Multiple choice – agree, disagree	14	
Cockburn et al. (1999)	9%	Unclear	8	
Ferrat et al. (2013)		Organic conversation	24	"Several" women recognised potential harm
Kissal (2011)		Semi-structured focus groups	2	One women expressed concern for radiation
Lagerlund et al. (2001)		Organic conversation	15	Concern was expressed in two non-attender[j] groups (eight groups in total) and cited as a main reason for non-attendance by one woman.
Mortality reduction efficacy (N=7)	% Correct			
Gigerenzer et al. (2009)	France 1.3% Netherlands 1.4% Italy 1.3% UK 1.9% Spain 2.7% Poland 0.8%	Multiple choice	France 20 Netherlands 20 Italy 7 UK 21 Spain 14 Poland 3	Q: How many fewer women die from breast cancer in the group who participate in screening, compared to women who do not participate in screening (out of 1000)
Domenighetti et al. (2003)	Q1. UK 22% Italy 17% Switzerland 24%	Multiple choice – 7-8 response options	UK 15, Italy, 1, Switzerland 4	Q1: The percentage of women correctly stated 5 deaths when asked how many deaths will be

	Q2: UK 3% Italy 4% Switzerland 5%			prevented out of 1000 women aged 50 who were screened biennially over 10 years. Q2. The percentage of women who knew the accurate morality reduction.
Baena-Canada et al. (2014)		Probability estimate	19	On average women believed 333 in 2000 women would avoid dying if they began regular screening from the age of 60, the true figure was reported at 1 death; a weak association between accurate knowledge and increasing age
Chamot et al. (2007)		Multiple choice – 6 answers	8	54% of women overestimated mortality reduction
Perceived necessity (*N*=10)				
Barratt et al. (1997)		Multiple choice – 3 answers	6	1.3% of participants thought screening is only for healthy women
Hersch et al. (2015)		Multiple choice – 2 answers	24	88% of participants thought screening is for healthy women
Baena-Cañada et al. (2014)		Multiple choice – 3 answers	19	91% of participants agreed screening is for healthy women
Luengo-Matos et al. (2006)		Multiple choice	4	95% of attenders and 74.6% of non-attenders agreed

				screening is necessary despite feeling well.
Cockburn et al. (1999)		Unclear	8	97% of participants thought they were eligible for screening regardless of symptoms
Villanueva et al. (2008)		Unclear	17	94.5% of women believed attendance is compulsory irrespective of the presence of symptoms
Van Agt Heleen et al. (2012)		Multiple choice- True, false, unsure	23	96.9% believed screening was compulsory
Chouliara et al. (2002)		Multiple choice – agree, disagree, unsure	14	100%d and 96.2%c of women believed if negative, further screening is unnecessary.
Lagerlund et al. (2001)		Organic conversation	15	In 4/5 non-attenders groups, the belief that screening is unnecessary in the absence of symptoms was raised.
Kissal (2011)		Organic conversation		A few women (number not specified) thought screening could cause cancer
Knowledge Score (*N*=11)	Mean (SD)/Max Score	Question Topics		
Soskolne et al. (2007)*	5.51 (1.92)/11	Recommended guidelines of mammography, risk of breast cancer	10	
Reder & Kolip (2017)*	2.79 (1.34)/7	Target group, meaning of false results, incidence of BC in screened and	12	9.8% had ‘adequate’ knowledge (scored 3 or more)

		unscreened populations, efficacy, overdiagnosis		
Mathieu et al. (2007)*	4.95(1.56)/10	Purpose, false results, incidence of BC in screened and unscreened populations	16	
Lagerlund et al. (2000)	3.6 (1.4)/8	Purpose and recommended screening frequency, breast cancer risk and factors associated with risk	14	55% of non-attenders and 63% of attenders scored 4 or more (adequate knowledge)
Hippman et al. (2015)*	3.2 (2.2)/8	Screening recommendations and breast cancer causes/treatment	27	No one scored ‘perfectly’
Berens et al. (2015)*	2.81(1.44)/7	Target group, frequency/meaning of false results, incidence of breast cancer/mortality reduced in screened and unscreened population, overdiagnosis	10	31.5% of participants had ‘sufficient’ knowledge (scored 3 or more)
Baena-Cañada et al. (2014)	2.97(1.16)/10	Purpose, false positives, efficacy, overdiagnosis	19	9.7% of participants were ‘reasonably informed’ (scored 5 or more)

Van Agt Heleen et al. (2012)	10.9 (1.7)/13	Purpose, choice to participate, meaning of false results, unfavourable effects, options following false positive and diagnostic assessment.	23	47.4% of participants have 'sufficient knowledge' (scored 8 or more)
Mathieu et al. (2010)*	6.27/10	Purpose, false results, incidence of BC in screened and unscreened populations.	19	83% of participants were 'knowledgeable' (scored 6 or more)
Ham (2006)*	8.41(2.47)/12	Purpose and recommended guidelines for screening, breast cancer risk and prevalence.	7	
Domenighetti et al. (2003)		Screening efficacy	UK 15, Italy, 1, Switzerland 4	In each country (UK, Italy & Switzerland) 1% scored 3/3. In the UK, 61% of participants scored 0, 68% in Italy and 54% in Switzerland.

Note. [a] non-attenders, [a] attenders, [c] 70-75 years, [d] 50-59 years, [e] 40-49 years, [f] non-opportunistic screeners, [g] 60-69 years, *contributed only a single knowledge score

Chapter 4: Subject Positions in Screening Mammography and Implications for Informed Choice

4.1 Chapter Overview

In this chapter I present a critical analysis of the discourse women use when discussing screening mammography. I present the analysis in its published form—as an article titled “Subject positions in screening mammography and implications for informed choice” in *Psychology & Health*. Through FDA this study sought to understand the “ways of being” (i.e., subject positions) that were made available to women by their discourse, and to examine the implications of these subject positions to informed choice in the breast health context. In doing so, the study complements the findings of Study 1 (Chapter 3) by beginning to address the second component of informed choice; exploring autonomy influencing factors, and facilitated the identification of relevant breast health professionals; information used for participant selection in Study 4 (Chapter 6). This published manuscript provides background and rationale for the research, a summary of methodology, presents identified subject positions, embedded within relevant literature, and highlights four implications for informed choice with associated suggestions for clinical practice and future research.

Seaman, K., Dzidic, P. L., Castell, E., Saunders, C., & Breen, L. J. (2020). Subject positions in screening mammography and implications for informed choice. *Psychology & Health,* 1–18. Advance online publication. https://https://doi.org/10.1080/08870446.2020.1766043

4. 2 Introduction

Mammograms examine women’s breasts using low energy X-rays for both screening and symptomatic purposes (Australian Institute of Health and Welfare [AIHW], 2019). In Australia, women aged 40 and over are eligible for a free mammogram biennially; however, the national program targets women aged 50-74 (AIHW, 2019). The utility of national mammography screening programs is debated in terms of the benefit/harm ratios posed to asymptomatic women. For example, benefits include the detection of smaller cancers, which typically increases treatment options, survival chances, and the likelihood of breast-conserving surgery; additionally, screening potentially reduces the use of hormone therapy and chemotherapy (Cancer Australia, 2015) and reduces breast cancer mortality by approximately 20% (Marmot et al., 2013). Potential harms include overdiagnosis (the detection of a tumour that would not have become clinically evident in a patient’s lifetime without screening; Pace & Keating, 2014), which can lead to unnecessary surgery, radiotherapy and other treatments; false positives, which are associated with both transient and persistent anxiety (Nelson et al., 2016, Salz et al., 2010); and pain from the mammogram (Nelson et al., 2016). The literature shows that women tend to overestimate the benefits of screening and underestimate the harms (Domenighetti et al., 2003, Seaman et al., 2018a), which poses implications for the ethics of mammography practice, specifically informed consent.

Informed consent requires a patient to have an accurate understanding of the benefits and harms of a procedure, and to make an autonomous decision free from the control of others (Beauchamp, 2011). In the context of screening mammography, many women report feeling ill-prepared when making a decision to screen (DuBenske et al., 2017) and feeling as if they are “following doctor’s orders” (Allen et al., 2013, p.6). Regarding health screening practices more broadly, men and women report feeling that they were absent from the decision-making process (Fowler et al., 2013). Decision aids, which aim to increase participant knowledge, may promote informed decision-making (see Mathieu et al., 2007, Mathieu et al., 2010, Smith et al., 2010) but informed choice requires more than accurate knowledge. For example, some scholars draw attention to factors such as the role of power inherent in the medical encounter (i.e., medical professionals are perceived as more powerful than patients; Lupton, 1997, Peterson and Lupton, 1996), the influence of social and political agendas (i.e., continued program funding requires high participation; Peterson and Lupton, 1996), and the role that emotions play in decision-making (Griffiths et al., 2010). As such, cancer screening participation is typically constructed by women and health professionals as an obligation, a routine practice, and a way to demonstrate responsibility to self, others, and society (Gibson et al., 2014, Griffiths et al., 2010, Howson, 1999, Solbjør et al., 2015, Willis, 2004).

To our knowledge, research exploring the experiences/actions that are available to women through the social construction of screening, and what these mean for informed choice, is limited. We noted brief commentary regarding implications to autonomy in Howson's (1999) exploration of women’s experience of cervical screening, and Willis (2004) and Solbjør's et al. (2015) explorations of women’s experiences of screening mammography. These authors showed that women who engage in screening were constructed as rational and good citizens whose duty is to minimise risk to self and others—together, these constructions strongly encourage attendance.

Our research and analytical approach draws from the work of Foucault (1972), who argued that the shaping of behaviour is achieved through the development of norms that impart a standard for how ‘good citizens’ should conduct themselves. Foucault believed norms are dispersed in a net-like fashion, thus highlighting the power inherent in everyday interactions and discourses and that translate into self-surveillance. For example, Risk

Discourses are well-researched within health contexts. Risk Discourses can moralise health behaviours and underscore intolerance towards citizens who do not take ‘appropriate’ health actions (Peterson and Lupton, 1996). In the context of screening, women who do not place their breasts and cervix under surveillance have been described as unintelligent, irrational, and lazy (Seaman et al., 2018b, Todorova et al., 2006) and can experience victim-blaming when diagnosed with breast and cervical cancers (Lupton, 1994, Gibson et al., 2016, Gibson et al., 2014). It could be speculated that women are under pressure to attend screening, which may obscure the opportunity for women to make a choice. In the context of screening mammography, we explore a) how attending (those who currently attend screening biennially) and non-attending women (those who do not attend biennially/have never attended) aged 50-74 discuss screening mammography, b) the subject positions made available in this discourse, and c) the implications for informed choice.

4.3 Method

4.3.1 Design

We adopted a qualitative design to explore women’s experiences of choice in screening mammography. One-on-one, face-to-face interviews were conducted to allow participants to share their stories and gain rich contextual data. Our constructionist epistemological position is aligned with the Foucauldian perspective in that Foucault (1972) was dubious of absolute truths, and acknowledged that the truth individuals construct is one of many available at the time and created from their socio-historical context. Conducting a Foucauldian Discourse Analysis (FDA) encouraged us to explore both dominating and resisting truths in women’s discourse, as well as legitimise individual experiences of informed choice in the screening context.

4.3.2 Participants

We recruited a convenience sample of English-speaking women aged 40 and over, currently living in Australia, and without a history of breast cancer. Women in this age group can access free screening mammography under the Australian National Breast Screening Program. Women with a history of breast cancer were excluded because of specialised screening and treatment they were/are likely to receive. As the terms ‘attenders’ and ‘non-attenders’ of screening vary throughout the literature, we define attenders as women who screen biennially and non-attenders as women who screen less frequently than biennially (i.e., 3+ years) or have never screened. These definitions align with research that often describes non-attenders as women who have missed their most recent screen (Aro et al., 2001; Chouliara et al., 2002).

The concept of data saturation, wherein no new ideas arise from the data (Hodges, 2011), was used to inform the sample size. Women were recruited from social media, yoga and dance classes, and a senior’s social club. We planned a minimum sample size of 12, based on Guest et al.’s (2006) recommendations, and the final sample comprised 16 women aged 44-72 years (*M* = 56.37, *SD* = 8.76). Eleven women were attenders of screening, while five women were non-attenders. Nine women were born in Australia, four in the United Kingdom, and one each in Italy, Japan, and New Zealand. For further demographics see Table 3.

Table 3. *Participant demographics*

	Participants (*n*=16)	
	N	**%**
Longest Place of Residency		
Australia	14	87.50
United Kingdom	2	12.50
Highest Level of Education		
Year 10 high school	2	12.50

Year 12 high school	6	37.50
Vocational Training	3	18.75
University degree	5	31.25
Has anyone close to you been diagnosed with breast cancer?		
Yes	9	56.25
No	6	37.50
No response	1	6.25
Previous work in healthcare sector		
Remedial massage therapist	1	6.25
Registered nurse	3	18.75
Medical scientist	1	6.25
Administration	2	12.50
No experience	9	56.25
Living Arrangements		
Single	2	12.50
Married/De facto	9	56.25
Living with children	5	31.25
Age		
40-45	1	6.25
46-50	3	18.75
51-55	5	31.25
61-65	2	18.75
66-70	3	12.50
71-75	2	12.50
Attenders*	11	68.75
Non-attenders**	5	31.25

Note: *Women who attend screening biennially, **Women who do not attend biennially/have never screened.

4.3.3 Interview Schedule

The semi-structured interview schedule was informed by literature and refined by the research team. Questions were open-ended with planned prompts to elicit further explanation. Questions were organised into seven categories: rapport building (e.g., Could you tell me what motivated you to participate in this research?), screening knowledge (e.g., Could you tell me any ways you know of that breast cancer can be detected?), perceptions of own breast health practices (e.g., Could you tell me about your own experiences with any breast cancer detection methods?), perceptions of breast health practices engaged in by others (e.g., How do you perceive women who do not engage in breast screening practices?), perceptions of Australia’s breast screening program (e.g., What messages related to mammography do you think they promote?), sources of breast screening information (e.g., Where do you go for breast health information?), experiences of informed choice (e.g., What does informed choice mean to you?), and shared decision-making (e.g., Could you describe any experiences related to shared decision-making about mammography?).

4.4.4 Procedure

The research was approved by the Curtin University Human Research Ethics Committee (HRE2016-0214). Participants were provided with the information sheet, written consent form, and a demographic questionnaire. Signed consent forms were returned before demographic questionnaires were completed and interviews began. Interviews were audio recorded, conducted at participants’ homes (*n* = 3), university campus (*n* = 5), and cafés (*n* = 8), and typically lasted between 25-30 minutes. Participants were thanked for their time and audio-recordings were transcribed verbatim. To maintain participant confidentiality, the demographic questionnaires were collected from participants and stored separately to their interview data. Following data analysis of all transcripts, participants were invited via email to provide feedback on preliminary findings.

4.4.5 Data Analysis

Interviews were conducted and transcribed, coded, and analysed concurrently until saturation (Hodges, 2011). Data was managed in NVivo version 10. From a Foucauldian perspective, discourses are sets of statements that may constrain or facilitate certain ways of speaking, thinking, writing, and being (Burr, 2003). Certain discourses are privileged over others, and legitimised through power relations and social structures. There are several ways to conduct FDA and we chose to adopt the six-step process outlined by Willig (2013). While reading each transcript, relevant excerpts were sorted into Willig’s steps that were preconfigured in NVivo as codes. This process was repeated until we felt confident in our interpretations.

To follow Willig's (2013) steps, we searched the data for the different ways in which our participants constructed the discursive object of mammography. In step one **(Discursive constructions)**, we identified two constructions (e.g., one positioned mammography positively, while the other viewed mammography negatively). In step two **(Discourses),** we located each construction in wider health discourses which served to help us understand why women discussed mammography in this way. In step three **(Action orientation)**, we explored what could be gained from constructing mammography in these ways, and within the wider discourses, and questioned the function of the constructions. In step four **(Positionings)**, we explored the subject positionings (i.e., ways of being) made available by the discursive constructions and wider discourses. We also considered the associated rights and duties of occupying particular discursive locations. In step five **(Practice)**, we considered the possibilities for action that were available to women who identify with a particular subject position. In the final step **(Subjectivity)**, we searched the data to understand how the subject positions impacted participants' experiences of informed choice. We chose to present our findings according to the three identified subject positions for several reasons—to best address our research aims (i.e., exploring subject positions) and as informed by our data; all participants identified and contributed to the subject positions indicating a shared meaning in our data, which we regarded as worthy of focal discussion.

Quality assurance processes included producing a comprehensive audit trail, analyst triangulation with the research team (i.e., a doctoral student, three experienced qualitative researchers, and a research-active breast cancer surgeon), and respondent validation (Locke and Ramakrishna Velamuri, 2009). Two participants provided feedback on preliminary findings, confirming they were satisfied with our interpretations.

4.4 Findings and Interpretations

This section presents the findings of our FDA according to the three subject positions identified in the analysis—the Responsible Woman, the Irresponsible Woman, and the Judicious Woman. Consideration and commentary on how these positions were made available and their function are also presented. The implications to informed choice are then explored in the Discussion.

4.4.1 The Responsible Woman

The Responsible Woman subject position is a woman who attends screening mammography and through this is characterised as taking responsibility for her breast health. In our data, this connection between attendance and responsibility appeared to be mobilised by the construction of screening as a helpful practice embedded within a Risk Discourse. For example, when participants discussed why they attended screening, they drew from a Risk Discourse in terms of viewing attendance as a central way to reduce risk of dying from breast cancer. In drawing from a Risk Discourse, the body was characterised as ‘at risk’: “Well, it [breast cancer] can affect any age. You see young women with it and even old women” (Attender) and “you're 50, you're bound to get it [breast cancer], so you better have a mammogram. That's the impression I get [from the screening invitation letters]” (Non-attender). These quotes demonstrate participants’ awareness that femaleness, or femaleness plus ageing, inherently poses risk to developing breast cancer. All participants conceptualised their bodies as continuously ‘at risk’ by these non-modifiable forces, which in turn drove their emphasis on the early detection of disease.

Both attending and non-attending participants endorsed the idea that the early detection of disease was a ‘good’ prospect, particularly as it could lead to improved survival chances: “If you catch it early, well, I think there's quite a high percentage of cure” (Non-attender), “obviously early detection is always going to be the best thing” (Attender), and “I think we know that early intervention is best. I mean, that's another message that's—we've been brainwashed" (Attender). The use of "brainwashed" serves to highlight the indoctrination to the idea that early detection saves lives, despite uncertainty regarding the predictive utility of screening on mortality rates due to lead-time bias and overdiagnosis (Nelson et al., 2016).

An important element of the Responsible Woman subject position is that participation optimises the early detection of breast cancer. Participants who attended screening viewed the mammography machine as something that could detect disease 'better' than the self. For example, an attender said, "I think usually we're in tune with our own bodies, you know, if something's not quite how it should be, but it's always good to get that official, 'You're clear'" and another attender stated she was eager to attend her next mammogram to determine the health of her breast following a recent fall: "I'm quite keen to have my mammogram to make sure everything's all right." In these quotes, the mammography machine is positioned as the expert of bodily surveillance and as ultimately responsible for the detection of any abnormalities. In response, the woman is displaced as the expert and requires the expertise of the mammography machine to authorise good health.

Through a status of good health, authorised by the mammography machine, a Responsible Woman is viewed as having reduced her risk of dying from breast cancer and is therefore a good citizen. Researchers note that the 'good citizen' arises from rhetoric in discourses such as Neo-liberalism, Healthism, The New Public Health, and Responsibilisation, whereby 'good citizens' are individual who take responsibility for their health for the benefit of self and others (Peterson and Lupton, 1996, Rose, 2009). Within these terms, assumptions are placed on the individual—good health is a result of the choices the individual made and requires self-control, and thus poor health is the result of individual failure (Rose, 2009, Peterson and Lupton, 1996). These assumptions underpin in the positive labels and praise that participants ascribed to the Responsible Woman. For example, a non-attender of screening said, “Good on them [attenders of screening] for being braver, I guess. They can do that. It’d be good on me if I could make myself do it,” and an attender of screening described herself as, “I’m quite tough, I'll just grin and bear it, you know? It’s [the mammogram] a bit uncomfortable, but you know, you just have to.” Toughness and bravery, qualities that require significant self-control in the face of adversity/discomfort, are linked to attendance of screening and to being a ‘good citizen’. The Responsible Woman occupies a moral high ground, as demonstrated in the following quotes when participants were prompted to consider how they perceive women who do not attend screening: “Well, look, I could be really harsh and just say stupidity [for not attending screening]” (Attender) and “I don't really think about it, but yeah, I think they're a bit silly” (Attender). Thus, non-attenders of screening are positioned as ignorant and/or irresponsible for not mitigating their risk of breast cancer via screening.

In being a Responsible Woman, the primary course of action is compliance with health professionals’ recommendations: “I was advised by the doc [General Practitioner (GP)] that it was time to have it [screening mammography] done, and have been having them done since” (Attender) and “Maybe because my GP told me it was time to have one done, really. No reason that I particularly sourced it out, or anything like that” (Attender). Many participants felt confident in following their GPs recommendations because “The firm line of it all is they know the latest research” (Attender), while some also felt confident due to a strong relationship with their GP as a trusted expert: “I know she's gone above and beyond to make sure that I'm well referred on or cared for. So, yeah, she's just someone I have a lot of faith in” (Attender). The positioning of GPs as experts draws from an Expert Discourse (Foucault, 1972, Lupton, 1997) that serves to drive and maintain the attendance by creating expectations of acceptable behaviour. This expectation of behaviour is seen in the following quotes by a non-attender of screening: “If you don’t [attend screening], they hound you a little bit. ‘We noticed you haven’t made your appointment.’ So, you know, there is that pressure, of, oh my god, I haven’t had my mammogram” and by an attender of screening when she was six months late for a biennial screen: “Well, I have to do as I’m told. I get a letter from the GP if I haven’t been, because they must notify your GP.” The use of “hound” constructs the mammography program as relentless in its efforts to get women to attend screening. The use of “I have to do as I’m told” draws from a Paternalistic Discourse whereby children are subservient to parents.

However, other attending participants drew on a Paternalistic Discourse to characterise the program as caring for them and the government (which funds the screening program) as guardians of women’s health: “I should look at the fact that they're [government] trying to guard your health and make you go and get something done that would either pick it up or not” (Attender). Inherent in this version of the paternalistic relationship is trust, which meant that some women had no interest in the decision to attend: “I don’t know anything about the harms. The benefits are, of course, finding breast cancer. I don’t even actually read about anything. Just go” (Attender), “it's [screening mammography] done so routinely, and it's been done for so long, I don't regard it as needing to be informed” (Attender), and “your GP should warn you if there's something wrong with you. I suppose you want to trust in the government” (Attender). These paternalistic constructions of health professionals indicate inherent trust, which for some drives their desire for health professionals to decide the appropriate course of action: “if I was having a conversation about having a mammogram, I would just want it to be a direct discussion of, ‘Yes, you probably should have one; no, I don't think you need one’” (Attender).

Attending participants’ experiences of choice in screening appeared to draw on an Expert Discourse and the desire for involvement in the decision to attend. Some participants described feeling satisfied in their access to and understanding of information about screening mammography: “I think if you actually read the documentation that is sent to you, or that you look at online, it [breast screening pamphlets] does say that [false positives]. It's pretty clear” and:

> I've definitely been given as much information as needed to understand fully what will occur … You’ve been told of the risks if you don't participate, and the risks involved in the procedure so then you can make your own decision if you want to have it done or not.

These participants described being able to make an informed decision. For some other attending participants, an Expert Discourse contributed to a desire for shared decisions with health professionals: “nobody can decide for you what you're going to do or what you're not going to do. Absolutely, I want shared decisions” (Attender).

4.4.2The Irresponsible Woman

The Irresponsible Woman subject position was identified, predominantly by attenders of screening, as a woman who does not engage in screening. This position, like the Responsible Woman, is mobilised by the construction of screening as a helpful practice within a Risk Discourse. This enables those who participate in screening to describe an Irresponsible Woman as “trying to be an ostrich and put her head in the sand” (Attender). The Irresponsible Woman, like the Responsible Woman, is characterised as being frightened by the prospect of breast cancer; however, rather than behave as a Responsible Woman, the Irresponsible Woman attempts to avoid screening and the possibility of finding breast cancer. According to some attending participants, screening avoidance may be due to fearfulness associated with finding breast cancer: “I know for some women, they don't take it [the invitation to screen] because they are scared of what they may find,” being “careless, reckless? I don't know. I can't understand why they [non-attenders] wouldn't have it done given that the risk factors [of screening mammography] and that, these days, are pretty low," and not health conscious: "I don't know anyone that is health conscious that doesn't, actually, go and have a mammogram" In the first quote, the participant draws from a Risk Discourse to emphasise the minimal risk associated with screening and position non-attenders as unreasonable in their avoidance. The construction of women as 'unreasonable' has also been reported by Kline (1999) in her analysis of media discourse on breast self-examination—she noted that women who did not practice self-exams were seen as foolish children and could be blamed for not reducing breast cancer mortality. In our data, through a Risk Discourse, "careless, reckless" or "health conscious" women may be vulnerable to blame if they developed breast cancer.

In considering the importance of being 'health conscious', several participants drew on a Parental Discourse when discussing their decisions to screen. For example, an attender of screening said, "I had these things running through my head that I was no longer married, so if something should happen to me, what would happen to my children, so it [attending screening] was driven by them, essentially, and their care" while a non-attender of screening stated, "the GP then sends me a [reminder] letter and then I think that they probably think that I'm a bit irresponsible, I've got children, and I think then I'm probably not being fair to them as well." The participants drew on a Parental Discourse that was also gendered to note that, by not taking the prescribed breast health action, they are risking their positioning as a 'good mother.' Rhetoric on motherhood in cervical and breast cancer screening emphasises a mother's centrality in the family (Gibson et al., 2016) and charges mothers with the responsibility of looking after the self so they may continue to care for the health of the family (Howson, 1999). As such, a 'good mother' is as a specific form of the 'good citizen' who engages in breast screening for the good of her family.

It is important to note that none of the women in our study described themselves as occupying the Irresponsible Woman position. Rather, this subject position was relevant only in terms of how they described other women or, in the case of non-attenders, recognised it as a label that may be ascribed to them by others. Further, although non-attenders might be seen as irresponsible, this perspective fails to account for contextual barriers affecting screening (e.g., culture/language, body image, lack of access, low health literacy; Sarma, 2013), nor does it appreciate risks from screening including false positives and overdiagnosis (Pace & Keating, 2014). Thus, this subject position may be more representative of the attenders' limited understanding of context and harms, which contributes to the perceived irresponsibility of those who do not screen. As our analysis is grounded in our participants' discourse, the courses of action regarding choice that are made available to the Irresponsible Woman can only be speculated. From our data, and the literature used to interpret our findings, we argue that not engaging in screening is unlikely to be a readily available option due to the potential for disapproval from several sources—medical, family, and societal.

4.4.3 The Judicious Woman

The Judicious Woman subject position was identified as a woman who takes responsibility for her breast health and engages in alternate risk-reducing behaviours. Like the Irresponsible Woman, a Judicious Woman does not engage in screening; however, through her engagement with other risk-reducing behaviours, she may mitigate the characterisation of her actions as careless and reckless. It is this active engagement in breast health behaviours that distinguishes her from Irresponsible Women. This distinction is outlined by one participant who attends screening, who stated: "I would be disgusted, actually, that they hadn't made some effort to make sure that they were okay."

The Judicious Woman is mobilised by the construction of screening as a potentially harmful practice. All participants described mammograms using terms like "painful" while non-attenders also expressed concern that the practice exposes women to radiation, thereby potentially causing cancer: “I've read, about cancer generally, that the mammograms could end up causing you to get the cancer” and:

> I think a lot of people think the same thing. Bumbling away in the back [of your mind] you think, "I wonder if this is doing any good." Or if there was something there, would this aggravate it, would this bolt of radiation activate it?

In these quotes, a Risk Discourse is used to describe screening as a potentially harmful practice. Non-attending participants also used a Risk Discourse to assess their own risk of developing breast cancer: “I don't consider that I'm at risk. I mean, I think maybe I've got my head in the sand, but I'm quite healthy, I do lots of exercise, and I eat really well” and “I mean, it's very occasionally, I might stand in the mirror and do this [breast awareness] to make sure there's no dimpling or orange peeling. I don't consider that I'm at risk.” In this way, Judicious Women are positioned as the expert on their own risk, where other risk-reducing practices, such as breast awareness, good nutrition, and engaging in physical activity, can be valued. Other non-attenders also challenged the assumption that screening is the optimal or only way to mitigate risk: “I think it's, in a way, if you're healthy and you are eating healthy and you’re looking after yourself, you're less likely to hopefully get cancer,” “I believe exercise is one of the preventable risk factors that can reduce risk. I think alcohol reduction, smoking and exercise are the three main ones,” and “I think self-examination is crucial as well, which I do do.”

The active engagement in these risk-reducing behaviours presented an alternate possibility of action—not to screen (at all or less frequently than every two years) and to engage in other practices and/or lifestyle factors that modify risk. As action is being taken to mitigate risk, it is possible that derogatory labels for these non-attenders may be mitigated. However, the Judicious Woman subject position still requires ongoing surveillance of the perpetually ‘at risk’ body, albeit from the self instead of the mammography machine. For example, participants occupying the Judicious Woman subject position (i.e., current non-attenders) spoke of the importance of self-monitoring their breasts and their risk: “I'm not too worried because I think it is a slow growing thing and you can check manually” and “If it’s within two years and I feel everything is okay, I don’t go. I go when I'm ready to go, or if I’m worried about something or if I feel something is not right, then I’ll go.”

In the context of the Responsible Woman subject position, the actions of the Judicious Woman are framed as defiant. For example, a participant who screens less than biennially said: “I'm a bit of a rebel, I just don't go, I go when I really feel like it.” In describing herself as a rebel, this non-attender recognises that she stands in opposition and resistance to an established norm—biennial screens. This well-established norm creates a need for non-attenders to justify their non-attendance: “I had it in my mind that it’s not in my family. I wasn’t at high risk [of developing breast cancer]. I didn't really need to do it [screening mammography].” Other non-attenders recalled dealing with pleas from their GPs: “She [GP] just said ‘Well just think about it. You have to think about it. Promise me you'll think about it’ and we were walking out to the waiting room and she's saying ‘Promise me you'll think about it’ and told me where to go” and “So she [GP] said as you get older, you really need to go get these things done.”

A participant appearing to occupy the Judicious Woman subject position also commented on lack of opportunity to engage health professionals in conversations about screening: “There’s no one to ask about mammograms, basically. You get your letter, and you make your appointment, and you go.” The establishment of biennial screening as the norm was described as hindering women’s ability to make an autonomous and informed decision about screening: “You have to really [attend screening], you’re bullied into it, with notes and reminders and all of that” (Attender) and “That’s the impression I got from the time when the [invitation] letter came through saying, "Now you’re 50, you have to have this screening” (Non-attender). For some attending and non-attending participants, the use of official channels of communication (i.e., letters/reminders/health professionals) to promote and reinforce screening, acts as a barrier to choice: “I think women do subject themselves to testing without fully understanding. I really do. Because the government sent you a letter” (Non-Attender) and “I haven't got a choice, I just get a letter” (Attender). A Judicious Woman is framed as a rebel who must stand in opposition and resistance to a higher authority, for her own cause, including autonomy over her body.

4.5 Discussion

In this study, we identified three subject positions or ‘ways of being’—the Responsible Woman (wherein most participants located themselves), the Irresponsible Woman (wherein no participant located herself), and the Judicious Woman (wherein the remaining participants located themselves). These positions were clearly defined and bounded as opposed to women shifting between positions. The Risk Discourse pervaded the subject positions and affected the health practices of women, leaving some to adhere to screening and others to resist it. In adopting these health practices, the participants “othered” alternative subject positions.

The Responsible Woman constructs screening as a helpful practice that reduces the risk of dying from breast cancer via early detection. Within this position, women are required to endure the discomfort of mammography for the benefit of self and others. Occupying this position may also offer a moral high ground whereby the construction of mammography as helpful can be used to delegitimise alternate breast health practices and label those who do not attend screening with negative characteristics. The Risk Discourse simultaneously promotes the duty of participating screening to lower risk of dying from breast cancer, and creates space for negative characteristics to be ascribed to those who may be risking missing a timely detection of breast cancer (Rose, 2009). Through an Expert Discourse, the mammography machine was seen as the authority in bodily surveillance, and thus most efficacious way to mitigate breast cancer risk. Through a Paternalistic Discourse, GPs/the government were cast as stern but caring parents who desire to protect women from breast cancer through the uptake of screening, and as such, encouraged compliance with screening. Together, these discourses act to legitimise screening mammography as the best practice of breast health and mobilise the Responsible Woman subject position—a woman who attends screening and is a 'good citizen'.

The Irresponsible Woman subject position describes women who take no action to mitigate risk of developing/dying from breast cancer as reckless to the self and others, and are vulnerable to experiencing blame from self and others (Brandt and Rozin, 2013). This vulnerability is supported by a recent exploration of 81 women's experience with cancer diagnosis (Gibson et al., 2017). The author reported that the women were socially positioned to take responsibility for their illness and were required to account for their illness and their role in its development. This subject position was made available by Risk and Parental Discourses. Through a Risk Discourse, women who do not engage in breast health behaviours were viewed as taking unnecessary health risks. Through a Parental Discourse, the presence of unnecessary risk taking meant that their fulfilment of the responsibilities of a "good mother" could be questioned. As such, the Irresponsible Woman is a woman who knowingly risks her health and whose actions are inconsiderate to society. It is important to note that none of the women in our sample identified themselves as an Irresponsible Woman but many were aware of her existence.

The Judicious Woman subject position describes women who engage in alternate breast health practices and demonstrate a degree of responsibility/care for self and others (i.e., family). Participants who occupied this subject position constructed screening as a potentially harmful practice that may increase the risk of developing breast cancer. Within this position, women are required to take responsibility for their health by engaging in alternate breast health behaviours, justify their decision not to attend screening, be attuned to their body to monitor risk, and heed health professionals' recommendations to screen. This subject position was made available through Risk and Expert Discourses. Like the Responsible Woman, the body was also viewed as perpetually at risk through a Risk Discourse. However, Judicious Women claimed expertise in understanding their individual risk and in remaining vigilant of their body to monitor risk. Through Risk and Expert Discourses, the mammography machine is displaced as the expert in risk mitigation, which enabled Judicious Women to create space to value and engage in lifestyle behaviours that are effective in reducing risk. Despite drawing from similar discourses as Responsible Women, and demonstrating responsibility for the care of self and others, Judicious Women were seen as deviant for their engagement in alternate risk-reducing behaviours. Participants who occupied the Judicious Woman position concluded that informed decision making is desired but was not always readily available.

4.5.1 Implications for Choice

Despite Australian women being invited to attend the national screening program, we argue that these subject positions available to women present limited choice. Our study suggests that, for many women, autonomous and informed decision-making is not an available option in the breast screening context which positions screening as the 'correct' breast health behaviour.

The emphasis on value of early detection meant that engaging in screening is lauded while opportunities to engage in alternate or additional risk-reduction strategies may be criticised. This dynamic is seen when Responsible Women are framed as such through their engagement in screening, while Judicious Women label themselves as rebels for engaging in prevention practices. It is thus entirely possible for a woman who attends biennial screening and eschews evidence-based, risk-reducing behaviours to be considered more responsible, be less likely to encounter negative labels for their health behaviours, and to feel pressured by health professionals, than women who engage solely in evidence-based, risk-reducing behaviours (Jones et al., 2011, Seaman et al., 2018b). Maintaining a healthy weight, being physically active, and limiting alcohol intake are evidence-based, risk-reducing behaviours to the development of breast cancer (Cancer Council Australia, 2018). The promotion of these whole-of-body health behaviours as legitimate options in breast health that either complement engagement in screening mammography or as legitimate in their own right, might present a possible future in which women’s choices regarding breast health (i.e., to only screen, to engage in only evidence based, risk reducing behaviours, or to engage in both) are better supported.

Shared decision-making might promote informed choice in the context of screening mammography. Shared decision-making is regarded as an effective way to renegotiate power and promote patient autonomy (Edwards and Elwyn, 2009, Fowler et al., 2013). However, research indicates shared decision-making seldom occurs in practice—in one study, 54.4% of women reported that providers did not explain breast screening as a choice, while 39.5% reported they were not consulted on their preferences (Fowler et al., 2013). In another study, shared decision-making was absent due to the limited provision of full information—women reported that 53% of healthcare providers discussed some/a lot of the benefits of breast screening, while only 8% discussed some/a lot of the harms of screening, with 92% discussing harms not at all/a little (Hoffman et al., 2014). Participants in our study reported a lack of shared decision-making because screening was described as an expectation undeserving of further discussion. However, there are several challenges in promoting shared decision-making—the variability in patients’ desire for shared decision-making as reported in by our participants and in other research (Joseph-Williams et al., 2014, Say et al., 2006), and the difficulties GPs face in facilitating shared decision-making (i.e., limited time with patients, uncertainty on accurate evidence, and conflicting personal values; Joseph-Williams et al., 2014, Parker, Rychetnik, & Carter, 2015, Siedlikowski et al., 2018).

Despite challenges, encouraging shared decision-making is warranted and we provide a potential framework—for example, it might be prudent that a standardised process of practitioner-patient interaction regarding screening be implemented. This process may begin with the acknowledgment that GPs or patients initiate the conversation, followed by an opportunity to discuss benefits and harms of screening. Following a decision, the GP should respect the woman's wishes by either ceasing the conversation or engaging in further discussion. Such a discussion should be accompanied by a standardised and accurate information sheet. Alternatively, decision-making tools could be used during the clinical encounter, which would be a contextually unique, yet potentially useful application—to date, these have been self-administered and either online, paper-based, or video-based (van Agt, Korfage, & Essink-Bot, 2014). However, Mathieu et al. (2010) outlined the applicability of these tools in supporting both women and physicians in the decision-making process, and Lewis et al. (2003) highlighted the importance of involving physicians in educating women about the benefits and harms of screening to counteract "women's enthusiasm" (p.10) for screening. Encouraging GPs to use decisions aids with patients, which explicitly outline that there is a decision to be made (Hersch et al., 2017), would harness the GPs' credibility and positioning as powerful, to construct screening mammography as a choice. Further to this, the use of decision aids during the clinical encounter may increase the likelihood that patients and providers enter the clinical space collaboratively through the tools endeavour to respect patient autonomy (Hersch et al., 2017). This dynamic represents a stark contrast to the 'bullying' to screen that may be experienced by some women and would challenge unequal power relations that may be entrenched in clinical encounters (Lupton, 1997).

The promotion of a shared decision-making practice also addresses the limits of a universal definition of informed choice. By definition, an informed choice is one made with autonomy, and with an accurate understanding of benefits and harms (Beauchamp, 2011); however, some of our participants felt satisfied with their decisions, despite limited understanding of benefits/harms. These instances create ethical complexities: should such a situation be viewed as acceptable compliance, the desirable exercise of women's autonomy, or as a failed attempt in engaging and supporting women within informed choice processes? These instances perhaps draw attention to the limits of a universal or decontextualized definition of informed choice (Ghanouni et al., 2016).

4.5.2 Limitations and Future Directions

Our findings should be considered in light of the study's context. For example, most participants reported Australia as their country of longest residency, and as such it is reasonable to assume the subject positions extracted from interviews are positioned in a Westernised understanding of screening and health. Furthermore, the subject positions are positioned within a context of a free national screening program. These programs do not exist worldwide and the discourses in countries without such programs might be very different. Further research is needed to understand the subject positions made available by those unfamiliar with national screening and if different health information needs exist within other cultures. It is also important to note that our sample had a higher percentage of women who attend screening than the Australia population; recent reports note 55% of women aged 50-74 attended breast screening from 2016-2017 (AIHW, 2019). Further to this, almost half of our sample was employed within the healthcare sector, and just over half had known someone with breast cancer. These experiences might explain why none in our sample adopted the Irresponsible Woman subject position—reports from a meta-analysis indicate positive attitudes about healthcare have a medium sized effect on intention to participate in disease screening, including mammography (Cooke & French, 2008). To ensure population views are represented more accurately, future research may benefit from purposive sampling regarding screening participation.

Given that some participants appeared to have a limited understanding of context and harms, which contributed to the perceived irresponsibility of those who do not screen, it would be prudent to explore the messages women receive from health professionals and the media. For instance, it is important to understand how GPs, who were identified in this study as crucial in fostering or impeding opportunities for choice, discuss screening with patients. This exploration may enable an understanding of the factors that influence their presentations of benefits/harms, and the practice of shared decision-making. This avenue for future research aligns with health movements that support informed choice and patient-centred care and aim to counter paternalistic and hegemonic medical practices (Corrigan, 2003, Hersch et al., 2017).

4.5.3 Conclusion

Our findings exploring the language women use when discussing screening mammography, how that creates ‘ways of being’, and what this means for informed choice align with Foucault's (1972) premise that power is socio-culturally created and enacted in everyday behaviours. Rather than promote the dissolution of a ‘correct’ choice, we suggest an expansion of the current discourse; one that promotes shared decision-making and a range of evidence-based breast health practices that can complement screening mammography, or be valued as legitimate health behaviours on their own. In expanding the legitimate practices available to women (i.e., beyond The Responsible Woman, Irresponsible Woman, and Judicious Woman), we hope to increase the number of women who experience screening mammography as a choice, to dissolve value-laden subject positions associated with non-compliance of screening, and increase the number of women engaging in risk-reducing behaviours. The pursuit of an expanded range of options ultimately offers an alternate future in which women’s autonomy to control their own bodies is encouraged.

Declaration of Conflicting Interest

The Authors declare that there is no conflict of interest

Funding

The authors would like to acknowledge the contribution of an Australian Research Training Program Scholarship in supporting this research.

Chapter 5: Subject Positions in Screening Mammography and Informed Choice: An Analysis of Contemporary Mass Media

5.1 Chapter Overview

In this chapter I present an analysis of contemporary mass media published or aired between February 2017 and February 2019. The unpublished manuscript complements the findings of Study 2 presented in Chapter 3 by also exploring the socio-cultural processes influencing informed decision-making in the breast screening context, and specifically in the context of mass media. Using FDA, I explored the subject positions made available to women and the opportunities for informed decision-making made available in 8 broadcasts aired by Australian free-to-air television and 61 articles published in state/national newspapers. The unpublished manuscript draws on feminist-informed theory to critique the “ways of being” made available to women in mass media and advocates for the continued critical analysis of mass media within the breast screening context. The findings of this study contribute towards recommendations for clinical practice and future research in Chapter 7.

5.2 Abstract

In this study, I explore the role mass media plays in constituting subject positions for women in the screening mammography context, and critically consider the opportunities for informed choice made available within these identified subject positions. I used FDA to analyse eight broadcasts aired by four Australian free-to-air networks, and 61 articles published in 11 state or national newspapers between February 2017 and February 2019. I identified three subject positions—The Vulnerable Attendee, a woman constructed as vulnerable to dying/developing breast cancer due to her femaleness and/or dense breasts; the Overdue Attendee, a woman who intends to screen, but is currently experiencing barriers in doing so; and the Obligated Attendee, a woman who feels grateful for the national screening

program and is positioned to screen in solidary with other deserving (i.e., Australian) women. Inherent in all subject positions was an expectation that a woman would screen, which has implications for informed choice.

5.3 Introduction

For Australian women, breast cancer is one of the most commonly diagnosed cancers, accounting for 27% of all female cancers (Australian Institute of Health and Welfare [AIHW], 2019). In an effort to reduce morbidity and mortality of breast cancer, Australian women aged 40-74 are offered free biennial 2D mammography as part of a national screening program (AIHW, 2019). It has been estimated that the program contributed to a 21-28% reduction in mortality (BreastScreen Australia Evaluation Taskforce, 2009). However, the utility of the national mammography program is debated due to the benefit/harm ratio posed to asymptomatic women (Nelson et al., 2016; Pace & Keating, 2014).

Research indicates that women tend to overestimate the benefits of screening and underestimate the harms (Collins et al., 2010; Seaman, Dzidic, Castell et al., 2018), with repercussions for informed choice. Informed choice requires that an individual should make a decision based on an accurate understanding of the benefits/harms of the procedure/intervention, and within an environment that supports an autonomous decision (Ells, 2003). The extent to which women are afforded an opportunity to engage in a process of informed choice in the screening mammography context has been questioned (Baum, 2006; Lau & Jaye, 2009; Seaman, Dzidic, Breen et al., 2018). Some researchers have sought to increase participant knowledge of screening through decision aid interventions, which have yielded an increase in the number of participants accurately understanding the benefits and harms of screening (Hersch et al., 2015; Mathieu et al., 2010). Endeavours such as these are important as poor health literacy is a barrier to good health (Berkman et al., 2011). However, ensuring people have access to quality, relevant, and easy to understand health information is necessary—but not sufficient—for client-centred care that promotes informed choice.

Mass media (i.e., television, newspapers, radio, online) is a central site in the production and transmission of health knowledge, and a powerful factor which shapes beliefs, thus experiences, of health and illness (Gibson et al., 2014, 2015, 2016; Lupton, 1994; McGannon et al., 2016). As such, mass media is recognised by feminist-informed researchers as a key socio-cultural factor which can shape women's experiences in the context of breast cancer/breast health (Gibson et al., 2014; Lupton, 1994). To my knowledge, an in-depth critical analysis of news representations of screening mammography, and the implications for informed choice, has not been conducted; however, several scholars have critically analysed the construction of breast cancer in media representations. For example, McGannon et al. (2016) reported that Canadian news constructed breast cancer as a biological entity that could be controlled or managed through the consumption of technoscience (i.e., technology which serves to regulate health risk through the development of cutting-edge technology, primarily surveillance technology) and personal responsibility. McGannon et al. (2016) noted this construction was mobilised by biomedical and healthism discourses which created three subject positions or "ways of being"—the breast cancer survivor, the good consumer, and the medical expert—which reinforced values of individual responsibility and self-control/regulation through the consumption of technoscience. In addition, they warned that the discourses and subject positions (re)create simplistic messages about breast cancer and technological consumption; that technology can effectively control and manage women's breast cancer risk (McGannon et al., 2016).

Analyses of Australian print media (Lupton, 1994), breast cancer lay material (Gibson et al., 2014), and Australian breast cancer websites (Gibson et al., 2015, 2016) show that women are positioned as responsible for surviving their breast cancer, and as active consumers (i.e., of services, technology, fundraising products) in their recovery and future wellness. Gibson et al. (2014) identified two intersecting discourses which endorsed women as having control over their illness; a discourse of individual responsibility and empowerment, and a discourse of optimism. Women were seen to be empowered when engaging in practices such as self-surveillance, exercise, and having a positive attitude. Lupton (1994) reported that asymptomatic women can be in control of preventing breast cancer by engaging in measures including lifestyle changes (i.e., exercise, non-fatty diet, having children “young”; defined by one data source as under the age of 25 years) and screening.

Although these discourses may be empowering for some women, they simultaneously position health as an individual responsibility, which serves to privilege the neo-liberal approach to health and can lead to victim blaming of individuals who do not engage in screening or change their lifestyle/attitude (Gibson et al., 2014, 2015; Lupton, 1994; McGannon et al., 2016). Lupton (1994) noted the media valorised screening and constructed it as the “answer” to reducing breast cancer deaths, which contributed to the neglect of adverse or risk information about screening, and the absence of information on alternate options, being presented in the media (i.e., mention of self-examination was absent).

I aim to further research that has analysed breast cancer messaging by focussing on screening mammography health information in Australian news media. Unlike preceding studies, we critically consider the implications of the identified discourses on women’s potential experiences of informed choice. An informed decision can only be made in an environment which supports autonomy. I align with feminism-informed researchers who reject bioethical perspectives of autonomy (i.e., those that privilege individualism, and abstract the self from the socio-cultural landscapes), and instead conceptualise autonomy relationally (Stoljar, 2000). Relational autonomy recognises that individuals are irrevocably influenced by their socio-cultural, historical, and political environment, rejects the notion of an independent sense of self, values decision-making in the context of relationships, and endeavours to support a diversity of experiences (Stoljar, 2000).

The research is informed by a Foucauldian perspective whereby discourse is seen as sets of statements which produce certain shared meanings (Foucault, 1972). Discourses have the ability to facilitate or constrain certain ways of thinking, speaking or acting, and as such, help to produce subjects who act and speak in a specified manner (Foucault, 1972). I am interested in examining how opportunities for informed choice in screening mammography are encouraged or inhibited through discourse. More specifically, the study aims to (a) explore the subject positions made available through discourse on screening mammography presented within Australian television news channels, and National /state newspapers from the last two years and (b) consider the implications of the subject positions/discourses to women’s possible experiences of informed choice.

5.4 Method

5.4.1 Design

I conducted this research by drawing on a social constructionist epistemological position and Foucault's (1972) work on discourse, power, and knowledge. Both social constructionism and Foucault assume multiple realities exist and emphasise the role of language in constructing social realities (Foucault, 1972; Galbin, 2014). Foucault (1972) considered discourse as sets of statements that create certain ways of seeing the world, and of being (i.e., subject positions). Foucault (1972) also identified the presence of dominant and counter-discourses, and believed power moves through discourses in everyday encounters and language. For example, an unwell individual may be labelled as a patient, leading them to occupy a passive position under the care of health experts; however, the individual may re-label themselves as a “fighter”, repositioning the self as an active agent in care and recovery (Willig, 2013). Foucault’s ideas on discourse, power, and knowledge are suited to analyses of news media as they regard everyday language as powerful, facilitate the identification of discourses, and lead us to consider the implications of these discourses. The research was approved by the Curtin University Human Research Ethics Committee (HRE2016-0214).

5.4.2 Data Selection

My decision to characterise discourse as written text in newspapers was determined by research conducted by Australia’s leading consumer, industry and market research company, Roy Morgan, which indicates 80% of Australians 14 years or older read newspapers (print or online) in an average seven day period (“It’s official: Newspaper masthead readership is up 3.2% to over 16 million”, 2018). Specifying discourse as television transcripts, as opposed to both verbal and visual means, prioritised the importance of discourse as well as to ensure the sample size remained manageable for in-depth qualitative analysis. I conducted the analysis within a two-year time frame (February 2017 to February 2019) because discourses change over time (Foucault, 1972; Galbin, 2014).

I consulted with a health science librarian to determine the best methods for searching Australian free-to-air television and newspapers. The databases used were TVNews-Informit, Factiva, and Australia & New Zealand Newsstream. TVNews-Informit indexes Australia free-to-air television news from 2008 and is updated daily. Factiva provides access to 32,000 sources including newspapers (local, state, and national). Australian & New Zealand Newsstream provides access to leading Australian and New Zealand newspapers.

I searched for television broadcasts within any Australian free-to-air station that was available in our chosen database, TVNews-Informit, and newspapers with high readership as guided by reports produced by Roy Morgan (“Australian Newspaper Readership, 12 months to June 2019”, 2019). For example, I selected the two highest read newspapers for each state/territory for weekdays and weekends, resulting, if possible, in four newspapers from each state/territory. Our search of these papers was then limited by their availability in our chosen databases. The final set of newspapers searched is displayed in Table 3. Of the 61 articles, 12 were published in 2017, 46 in 2018, and three in 2019. Of the eight broadcasts, five were aired in 2017 and 3 were aired in 2018.

Table 4. *Newspapers and Television Stations Searched and Data Source Characteristics*

Newspapers searched			**Television broadcasts searched**	
State/Territory	*Newspaper*	*Number in final sample*	*Television Network*	*Number in final sample*
Nationwide	The Australian	0	SBS News	1
New South Wales	Daily Telegraph	10	Ten News	2
New South Wales	Sunday Telegraph	0	National Indigenous Television Australia	0
New South Wales	Sydney Morning Herald	3	Nine News	2
Northern Territory	Northern Territory News	0	Seven News	3
Northern Territory	Sunday Territorian	0	ABC Television	0
Queensland	Cairns Post	4	Sky News	0
Queensland	Courier-Mail	8		
Queensland	Gold Coast Bulletin	6		
Queensland	The Sunday Mail	0		
South Australia	Adelaide Advertiser	10		
South Australia	Sunday Mail	0		
Tasmania	The advocate	2		
Tasmania	The Examiner	1		
Tasmania	The Mercury	0		
Victoria	Herald Sun	7		
Victoria	Sunday Herald Sun	0		
Victoria	The Age	2		
Western Australia	Sunday Times	0		
Western Australia	West Australian	2		

5.4.3 Inclusion and Exclusion Criteria

Television broadcasts and newspaper articles were included if the focus was on screening mammography, attendance rates of screening mammography, advertisements for BreastScreen Australia, information on risk factors including genetics and breast density, new breakthroughs (provided some mention of screening mammography was included), and if the target audience was asymptomatic women of any age. Broadcasts and articles were excluded if their focus was breast cancer, diagnostic mammography, cancer diagnosis/survivorship, and for articles specifically, if their content was an opinion piece, or letter to the editor.

5.4.4 Data Extraction

As detailed in Figure 4, I used the same search terms in each database and the same search parameters where possible. To ensure broadcasts were not missed through an overreliance of TVNews-Informit, we searched each television networks website archives. This yielded no new video broadcasts. To determine the suitability of the broadcasts and articles, I viewed all 11 videos and read all 215 articles in full. Their content was analysed against the mediums inclusion/exclusion criteria, with decisions to retain or reject documented in a excel spread sheet. A random 10% of the total number of identified broadcasts (n = 5), and articles (n = 21) were assessed by a supervisor to confirm the data was accurately assessed against the inclusion/exclusion criteria, leading to very high inter-rater reliability (Cohen’s Kappa of 1 for broadcasts and 0.9 for articles). The final sample comprised 8 broadcasts and 61 newspaper articles. Broadcast transcripts I could not locate were professionally transcribed. Article word length ranged from 50 to 1876 words (M = 331.26, SD = 279.42). Length of broadcast segment ranged from 26 to 157 seconds (M = 74.37, SD = 47.32).

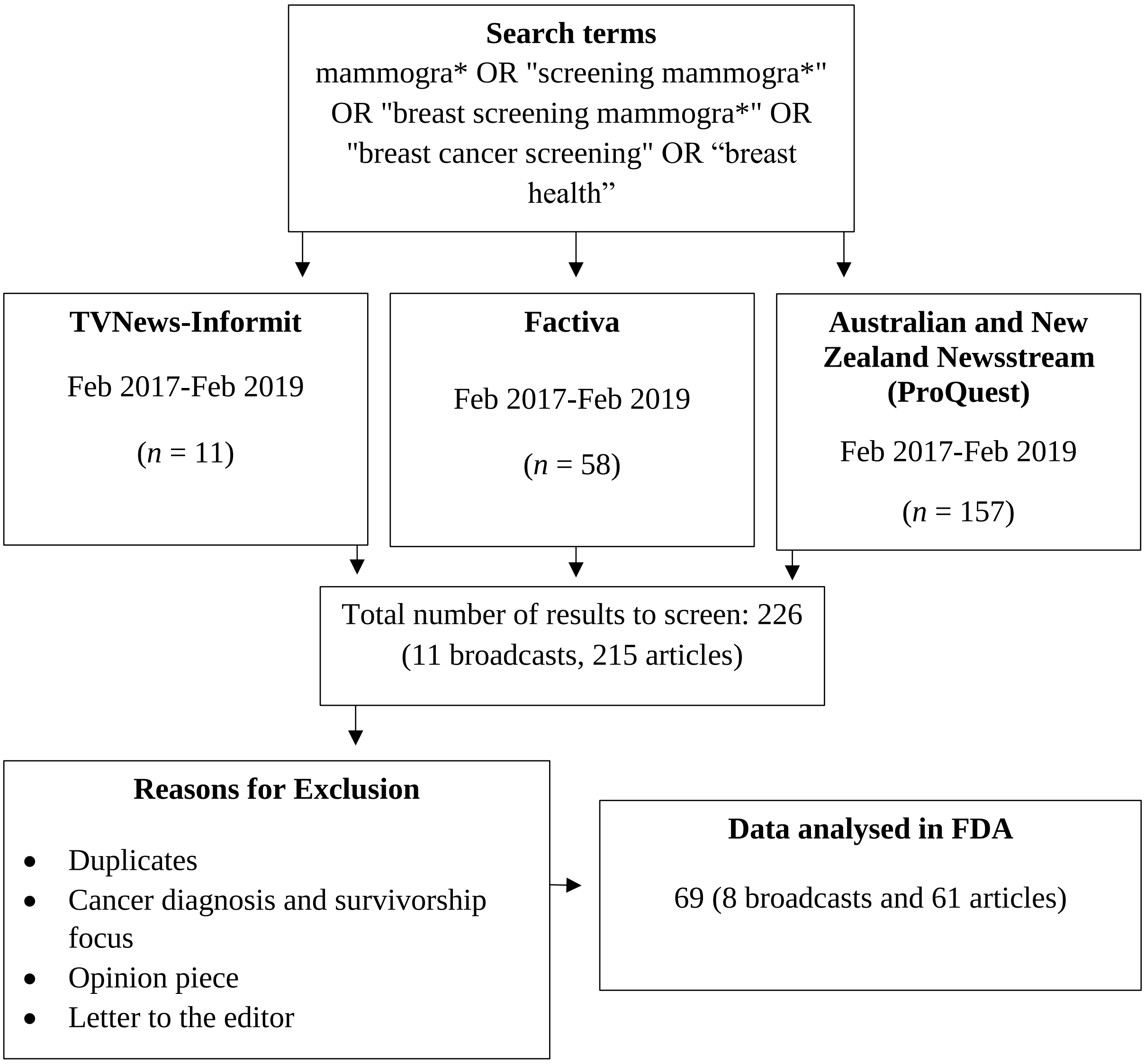

Figure 4. Flow Chart of Study Selection

5.4.5 Data Analyses

I applied FDA to the textual components of television broadcast transcripts and newspaper articles. We followed the six steps outlined by Willig (2013) to identify how screening mammography was constructed. In step one (*Discursive constructions*), I identified two constructions of screening mammography (e.g., one positioned mammography positively, while the other viewed mammography negatively). In step two (*Discourses*), I located the constructions of screening in wider discourses which helped us to understand what could be possible for women within these discursive spaces. Wider discourses were chosen by considering the context in which mammography was discussed (i.e., constructions of screening as positive or negative were often associated with risk increases/reduction, hence were located in a wider discourse of risk). Next (*Action Orientation*), I considered what function the discursive constructions and wider discourses have; what could be gained from constructing mammography in this way through this discourse? In step four (*Positionings*), I identified subject positions, or "ways of being" which were made available by the discursive constructions and wider discourses. In doing so I also considered what rights and duties were associated for individuals occupying this space. In step five (*Practice*), I identified how readers were encouraged to speak, think, and act from the positions. In the final step (*Subjectivity*), I considered how the practices associated with subject positions encouraged or inhibited opportunities for an informed choice.

5.5 Findings and Interpretations

In aligning with my aims, I present the findings of our FDA according to the three subject positions identified—the Vulnerable Attendee, the Overdue Attendee, and the Obligated Attendee. Furthermore, we critically consider how these constructions came to be, the practices available to women from this position, and provide commentary on their role in opening or closing opportunities for choice. I present commentary on the implications for informed choice in the Discussion.

5.5.1 The Vulnerable Attendee

The Vulnerable Attendee was identified as a woman vulnerable of developing/dying from breast cancer due to her femaleness and/or her dense breasts. Throughout my data, breast cancer was discussed as a serious and very common disease in women. For example, "One in eight women will be diagnosed with breast cancer by the age of 85" ("Book Online," 2017, p. 27) and “More than 17000 Australian women are diagnosed with breast cancer each year” (“Cancer Diagnosis,” 2017, 0:27). In these excerpts, women are constructed as being vulnerable to developing/dying from breast cancer due to their femaleness. Only one author noted that both men and women were vulnerable to developing breast cancer: “An estimated 18,000 women and 150 men will be diagnosed with breast cancer this year, according to the Australian Institute of Health and Welfare” (“Stepping forward for 3D mammography,” 2018, p. 29). As such, the principal message was one that constructs a woman’s body as risky. According to the discourse of Risk, which grew from the dissolution of the health/disease dichotomy in the 20th century (Armstrong, 1995) and remains prominent in contemporary health talk, those with risky bodies are expected to act to mitigate their risk in the interest of the self and others (Crawford, 1980). For example, the presence of such rhetoric can be seen in the following statement, “Early detection not only improves health outcomes, it reduces overall costs to the health system and, most importantly, saves lives” (Crouch, 2018, p. 18). As such, a state of good health is seen to be the result of an individual engaging in early detection; this individual is then regarded as a “good” citizen (Crawford, 1980, Peterson & Lupton, 1996).

In considering what it means for women and men to be “good” citizens in the screening mammography context, I noted several ways in which women were encouraged to mitigate their risk of breast cancer, while noting that men’s mitigation was absent. Ways in which women were encouraged to be “good” citizens stemmed from gendered discourses, which reinforced gendered responsibilities. For example, in an article about upcoming fundraising efforts for breast cancer research: “Breast cancer steals mothers, daughters and girlfriends too soon. It robs wives, sisters, aunties, grandmothers and work colleagues of life” (O’Connell, 2018a, p. 8), and in a broadcast, which spoke of advances in screening technology (3D mammography): “Regular mammograms [2D] were not enough to save Ali's mom, Betrina. A deadly lump in her breast was detected too late" ("Density risk," 2017, 0:15). In these excerpts, women themselves are not sufficiently worthy to warrant their own identity; rather, their identity and worth is in their relationship to others (i.e., as a mother, wife, daughter, grandmother, sister, friend). These extracts perpetuate the moralistic quality of engaging in mammography; a woman who does not engage threatens not only her life, but also loved ones she may burden with disease and death. This consequence is located within historically gendered roles which position the care of others as women's responsibility (Gilligan, 1982/2009). Other studies, which focused on exploring women's narratives in relation to breast and cervical cancer, reported that women felt this responsibility to others when considering engaging in screening, and throughout their cancer diagnosis/treatment (Gibson et al., 2016; Howson, 1999).

Women were identified as being more vulnerable to developing/dying from breast cancer if they had dense breasts. For example, "Women with very high breast density are four-to-five times more likely to develop cancer than women with the least dense breasts" ("Breast density crucial in reducing risk of cancer", 2018, p. 17) and "Women with dense breasts are four to five times more at risk and also are more likely not to be detected by a standard mammogram, when compared to women with average density" ("New data out today," 2017, 0:07). In these excerpts, dense breasts are constructed as highly problematic breasts, and 2D mammography is constructed as inadequate to detect cancer in dense breasts. The efficacy of 2D mammography was questioned in articles and broadcasts, for example as stated by Imaging and Medical Beamline principal scientist Dr Daniel Hausermann, "There is a lot of inspired guess work when there is a blurry mass in a normal mammogram" (O'Connell, 2018b, p. 18) and, by a news presenter, "A new high-tech machine promises to detect breast tumours that are sometimes missed in [2D] mammograms" ("New screening for breast cancer," 2017, 0:01). Media promoted 3D mammography as the solution to these highly problematic breasts. For example, “Some studies show that more than 40 per cent more cancers are detected, there is a reduction in unnecessary biopsies performed and, false positive results are reduced with 3D mammography” (“Stepping forward for 3D mammography,” 2018, p. 29). The excerpt highlights the inadequacy of one technology and promotes the efficacy of another, which has the potential to reinforce simplistic messages about breast health; for example, that technology consumption will effectively manage women’s risk of breast cancer (McGannon et al., 2016).

Several media texts actively encourage the Vulnerable Attendee to seek out the most efficacious risk reduction technique. For example, “Experts want every woman when getting a mammogram to ask if they have dense breasts. And if the answer is yes, to then discuss with their GP whether an ultrasound 3D mammogram or MRI should be the next step” (“Density risk”, 2017, 1:08), and “‘Women across the country are telling us, in no uncertain terms that they expect their healthcare professional to tell them if they have dense breasts,’ Krystal Barter, chief executive of breast cancer group Pink Hope, said” (Dunlevy, 2018, p. 3). In each excerpt, women are positioned as responsible for eliciting information about breast density from health professionals. In this way, women are encouraged to operate from discourses of Individual Responsibility and Neoliberal Consumerism; a space where consumer choice is seemly possible, and in fact encouraged (Gibson et al., 2015). The need for women to advocate for the self is further emphasised in some articles which characterise governments as unwilling to disclose information on breast density:

> Two million women who are at higher risk of breast cancer are being denied crucial information that could help protect them from the disease. Australia is lagging behind the US by failing to inform women about the density of their breasts after a mammogram. (“Breast density crucial in reducing risk of cancer”, 2018, p. 17)

> A new survey of more than 1000 women found seven in 10 think it is unfair they are not told about their breast density. And it's a political issue, with one in two women more likely to vote for a government that made medical information about breast density a priority. (Dunlevy, 2018, p. 3)

In these excerpts, emotive terms such as "denying," "lagging behind," "failing," and "unfair" are used to cast the government as not caring for women's health, and women as vulnerable from the governments' lack of care. From this, women are positioned as vulnerable yet, in a way, potentially powerful. Interestingly, these statements may contrast the discourse of individual responsibility that is often reported in breast cancer/health discourse (e.g., breast wellness is a woman's responsibility; Gibson et al., 2014; Lupton, 1994; McGannon et al., 2016), and might encourage collective action to counteract the Australian Government's apparent downfalls.

However, there is no standardised or reliable way to measure a woman's breast density or predict the associated risks (i.e., likelihood of breast density masking cancer during a mammogram or likelihood of developing breast cancer; Cording, Smith, Gribble, & Bishop, 2018). New technologies providing automated measures of breast density, as opposed to relying on individual radiologist's opinion, are being developed; however, due to their expense, are currently not used Australia-wide (Cording et al., 2018). In addition, although evidence suggests breast density increases the risk of developing breast cancer, there is a lack of evidence that outlines how this can be reduced (Cording et al., 2018). Therefore, clinicians remain unguided on how to care for women identified as having dense breasts (Cording et al., 2018). Only one article in my data attempted to communicate this uncertainty through a quote by Sydney Breast Clinic chief radiologist Professor Mary Theresa Rickard, who similarly concluded that the onus is on the individual woman to advocate for her own health:

> In Australia the way to manage breast density has not yet been formally agreed to and so our lack of public education and one-size-fits-all approach to screening with standard mammography only persists. We need women to know this if they're to be their best breast advocate. ("Breast density an important part of check," 2017, p. 4)

5.5.2 The Overdue Attendee

The Overdue Attendee was identified as a woman who is yet to attend screening; however, once barriers are removed, will do so. Within this subject position, screening is constructed as a practice which can significantly reduce a women's risk of dying from breast cancer. For example, in an article, Cancer Council South Australia chief executive Lincoln Size said "For women diagnosed with breast cancer, the risk of death was 42 per cent lower among those diagnosed through BreastScreen Australia than those who had never screened" (Crouch, 2018, p.18), while in another article, the author stated, "Annual mammograms from age 40 will reduce breast cancer deaths, a major study has found" ("Early tests beat cancer," 2017, p. 5). These excerpts draw on Scientific and Risk discourses to construct women who screen as rational health care consumers; women who reduce their risk of dying from breast cancer via understanding of and guidance from evidence-based literature.

As all women are assumed to be rational and to ascribe to Western medical discourse, a woman who does not screen is considered unable rather than unwilling. A main barrier to attendance identified in my data was women having an inaccurate perception of the risk of developing breast cancer, "Women tend to have a perception breast cancer is common but don't think it will happen to them, Ms Kay [From BreastScreen New South Wales] said. That's why it can be easy to forget to schedule a mammogram or not make it a priority" (Hamilton-Irvine, 2018, p. 27). Another main barrier to attendance identified was busyness, "No doubt, many other women have heard the announcement [BreastScreen Australia campaigns] but have still chosen to prioritise Christmas preparations over looking after themselves and their own health [speaker: Jane Burden, General Manager of BreastScreen, South Australia]" (Gilbertson, 2017, p. 9). While a final barrier to attendance related to culturally specific barriers:

> In my community [Indian and Sir Lankan], women tend to be very focused on supporting the health of everyone in their family, but don't tend to think about themselves,' Shantha [Pink Sari president] said. Modesty also stops them, along with fear, a lack of awareness, and a tendency to keep quiet about personal health matters (Albulario, 2019, p. 26).

These quotes provide examples of some barriers that women are believed to be experiencing, which contributes to the belief that women will engage in screening, but are merely overdue. In addition, the last excerpt demonstrates the media's particular focus on constructing women from culturally and linguistically diverse backgrounds as more likely to be Overdue Attendees compared to women from Australia's dominant cultural group—white English-speaking Australians. This standpoint is demonstrated in several excerpts where the attendance of women from diverse cultural backgrounds was highlighted. For example, "Numbers are particularly low among Arabic-speaking women, with thousands not having a mammogram in the past two years" ("Many women are still not being tested for breast cancer," 2017, 0:03), and "With early detection a key factor in breast cancer survival rates, this equates to thousands of women at risk of undetected breast cancer in one of the state's largest migrant communities, the problem stems from several factors" (Albulario, 2019, p. 26). In these excerpts, women from diverse cultural backgrounds, and their screening choices are constructed as a "problem" to be solved. I suggest that the focus on culturally diverse women in this way serves to further marginalise and problematise particular cultural groups;

a suggestion also reported in Gibson et al.'s (2016) examination of four Australian breast cancer websites, which focused on exploring how women from minority groups or culturally diverse backgrounds were represented. In the screening mammography context, such marginalisation serves to limit the opportunity for non-Western knowledge on breast surveillance to be seen as valuable and reinforces the dominance of Western medical discourse (Gibson et al., 2016).

The dominance of medical discourse, one which constitutes "good" breast health practice as screening, is reinforced via the media's presentation of "solutions" to Overdue Attendees' non-attendance. For example, one suggestion was that booking an appointment could be made quicker and easier, "BreastScreen WA is trying to boost the number screened by introducing an online booking system during next month's breast cancer awareness month" (O'Leary, 2018, p. 16). Another suggestion was that specific cultural groups' concerns about screening could be addressed through promoting the practice of screening via key community members: "[Speaker: Naomi Combe, program manager Breast Screen New South Wales] What we hope to do is engage with women, especially using champions from their own communities to talk them around and explain to them that there's no need to be concerned about the various different barriers" ("Many women are still not being tested for breast cancer," 2017, 1:31). Also highlighted was the program's financial accessibility by being "free" ("Do you need screening?" 2018, p. 18; Hamilton-Irvine, 2018, p. 27). These messages convey the notion that screening is the socially-sanctioned breast health practice and that the Overdue Attendee does not attend screening due to structural, social, and/or individual barriers, as opposed to having made the choice not to attend. Such barriers were identified in a narrative review of barriers to women attending screening mammography in the United States, which described barriers within the healthcare system (e.g., lack of health insurance and service availability), society (e.g., lack of social support, cultural norms of modesty), and individual (e.g., limited knowledge about harms/benefits of screening, negative experiences with healthcare systems; Sarma, 2013). An Australian study exploring reasons for non-attendance among women from culturally diverse backgrounds reported emotional (e.g., anxiety related to personal beliefs and past negative experiences with health professionals) and structural barriers (e.g., difficulty accessing services; O’Hara et al., 2019). Efforts to reduce barriers for women may create an environment where screening services are more easily accessed, and perhaps, for women from culturally diverse backgrounds may even serve as a means of inclusion rather than marginalisation.

However, by solely constructing a woman’s absence in the screening program as a result of encountered barriers, non-participation cannot be regarded as a legitimate and autonomous choice. As such, if an Overdue Attendee does not attend screening, her behaviour is explained according to the presence of barriers. Research has reported psychosocial consequences experienced by those viewed as having rejected engagement with health behaviours. For instance, women living with cancer have reported feelings of blame/shame due to perception (by self or others) that they were not diligent in risk management (e.g., diet, smoking, and “timely” health checks; Gibson et al., 2017). Similarly, women who do not participate in screening mammography may be described as lazy, uncaring, and irresponsible (Seaman, Dzidic, Breen et al., 2018). Thus, the Overdue Attendee stands to lose her status as a “good” Australian woman.

5.5.3 The Obligated Attendee

In the Obligated Attendee subject position, women are expected to engage in screening. For example, in a broadcast, New South Wales Minister for Health Brad Hazzard said “Citizens of Australia do get a free breast screen if you're over 40 years old. And if you're between 50 and 74, we're actively telling you, you must have one” (“Screening loophole," 2018, 1:31). Women are also expected to be grateful for screening mammography because of the Australian tax payer dollars that have been invested, "Australian taxpayers have invested a great deal of money into research to eliminate breast cancer. One of the prime elements of that investment over many years has been expanded screening to detect the earliest possible signs of this insidious disease" ("Stop the breast screen rort," 2018, p. 34). Other research has reported women feeling grateful for the presence of and/invitations to national screening mammography programs (Østerlie et al., 2008; Seaman et al., 2020).

Also in the subject position of the Obligated Attendee, women are obligated to engage in screening to protect the use of mammography from use by non-Australian women, and protect Australian taxpayer dollars from being spent on women who are discursively constructed as not deserving of the monetary investment in this technology. For example, a broadcast discussed "A potential loophole which allows foreigners to get free mammograms in Australia is now under review, but while the government wants to stop scammers, it says the priority is not deterring other women from having the lifesaving examination" ("Screening loophole," 2018, 0:01) while a newspaper article noted that "This means that Australia's investment in the health of the nation's women is being stretched because other nations are nowhere near as committed to taking action" ("Stop the breast screen rort," 2018, p. 34). The excerpts are referring to a practice termed medical tourism, in which people travel to other countries for obligatory or elective medical treatment (Eissler & Casken, 2012). Research indicates that travel is undertaken due to long wait lists, significant costs, or unavailability of services/treatments in the country of origin (Leahy, 2008). The excerpt above constructs medical tourism as placing a strain on BreastScreen services; however, as stated by Professor Currow [Cancer Institute New South Wales, CEO] "because no data was collected, the extent of the problem could not be quantified" (Lynch & Fife-Yeomans 2018,

p. 9). Statistics on global medical tourism are unreliable (Greenfield & Pawsey, 2014) yet underscore calls for Australian resources to be used only for Australian residents:

> New South Wales Health Minister Brad Hazzard told The Saturday Telegraph mammograms should be available to foreigners if there was an emergency need. "But if there are travel agents or travel companies out there organising these free mammograms as part of what is essentially a breast tour rort, we will do all we can to stamp out the practice," he said ("Screening a lure for foreigners," 2018, p. 9).

> Breast cancer survivor Claire Roberts, 43, said that the authorities needed to draw a line in the sand. I think it should be for residents," she said. It gets crazy this health tourism, people going to other countries to get health services. Where do you draw the line? If you're taking a mammogram then what is next? People thinking I will have my treatment here now too (Lynch & Fife-Yeomans, 2018, p. 9).

In the first excerpt, the use of "we" calls for collective action to "stamp out the practice", while the second excerpt outlines the deserving collective as Australian "residents". These discursive techniques create a tension where expected consumers of mammography are encouraged to utilise the technology under a guise of solidarity, but only to women deemed deserving (i.e., only Australian women). The tendency for women to participate in screening in solidarity for other women has been reported by Willis (2004) wherein women in rural communities regarded their screening participation as a social responsibility. More specifically, failure to attend could threaten the future viability of providing the mobile screening van for women in the community.

The statements presented within this subject position also perpetuate sanctioned racism and ethnocentrism through a Nationalist discourse. For example, the discourse promotes the exclusion of others via negative representations of non-Australian women as “scammers” and on a “breast tour rort”; such language delineates Australian women as deserving, and non-Australian women as undeserving. Doing so draws upon ethnocentrism, which is the tendency to regard one’s own culture and people as superior to others (Keith, 2013) and sustains oppressive power relations between dominant and non-dominant groups. Overall, the tensions identified draw from the construction of screening mammography as an expensive and valuable investment on part of the Australian taxpayer, for Australian women.

5.6 Discussion

In this article, I identified three subject positions made available in Australian print and television media between 2017-2019 when discussing screening mammography—the Vulnerable Attendee, the Overdue Attendee, and the Obligated Attendee. Overall, media depictions of screening mammography position women as attendees, problematise non-attendance (unless the woman is not an Australian citizen), and limit women’s ability to choose not to attend screening.

Within the subject position of the Vulnerable Attendee, the media constructed a woman’s body as at risk of developing/dying from breast cancer due to her femaleness and/or dense breasts. To reduce the risk of dying from breast cancer, the Vulnerable Attendee is positioned to screen her breasts with 3D screening technology, which was constructed as superior to 2D mammography. However, access to 3D mammography appeared to be blocked by the Government, who were constructed as failing to provide the service to women. As such, the Vulnerable Attendee was positioned to lobby against the Government to access 3D screens, which we argue, reinforces the privileging of medical technology in monitoring women’s bodies, and managing breast cancer risk (McGannon et al., 2016). It was important for the Vulnerable Attendee to manage breast cancer risk to maintain her gendered identity (i.e., as a mother, sister) which is bound within the responsibility of care for others (Gilligan, 1982/2009).

The Overdue Attendee is underpinned by a Risk discourse, and the rationality entrenched in the dominant medical discourse. The rationality in the medical discourse constructed screening as an evidence-informed, risk-reducing practice, thus positioned women who attend screening as rational healthcare consumers, and women who do not attend as merely Overdue Attendees. The media cited barriers and solutions to attending screening, which for some women, may be accurate of their experience, and assist them to screen (O’Hara et al., 2019; Sarma, 2013). In addition, the media specifically identified women from culturally and linguistically diverse backgrounds as women likely to be Overdue Attendees. The specific focus on women from diverse backgrounds serve to “other” these groups and reinforce the dominance of Western medical knowledge within breast health.

Within the subject position of the Obligated Attendee, screening was constructed as a valuable and expensive Australian resource. From this, the Obligated Attendee is expected to participate in the national screening program and feel grateful for the investment of the Australian taxpayer in funding the program; feelings which have been reported in prior research when women spoke about national screening mammography programs (Østerlie et al., 2008; Seaman et al., 2020). The Obligated Attendee is also expected to protect the program from “undeserving” participants, identified, by the media as “scammers”, or more accurately, non-Australian women. I argue the terms used by media provide evidence of a nationalist discourse which perpetuates racism and ethnocentrism. Overall, the Obligated Attendee is positioned to screen in solidary with other “deserving” women.

I noted that at any one time, a woman may occupy one or all of the identified subject positions. For example, a woman’s subject position was consistently bound within the Vulnerable Attendee; the subject position which locates women as needing to screen to manage their perpetual risk of developing/dying from breast cancer. As such, whether a woman is occupying the subject position of the Overdue and/or Obligated Attendee, they remain a Vulnerable Attendee. It may be possible for women to occupy all subject positions simultaneously—a woman is perpetually vulnerable to developing/dying from breast cancer, is expected to attend screening, and to feel grateful for, and protected by the provision of the service for Australian women. It is important to note the fluidity of subject positions to highlight that there are many "ways of being" available to women at any time; however, all subject positions limit the choice not to attend screening. This finding gives further importance to constituting a subject position that offers choice in the screening mammography context.

5.6.1 Implications for Informed Choice

Inherent in all identified subject positions is the assumption that screening mammography is not something requiring choice; rather, it is something in which women 40 years and over will engage. In documenting the subject positions described within contemporary Australian media, this research finding contributes to emerging literature which has reported a lack of choice available in screening mammography (Seaman et al., 2020). Further, it adds momentum to calls for the critical consideration of informed decision-making practices in cancer screening (Ells, 2003; Hersch et al., 2017).

Another key implication relates to the finding that, in all identified subject positions, women were positioned to screen to serve the interests of others. For example, the Vulnerable Attendee's screening increases the chances that she is able to continue existing in the lives of others as a mother, sister, and aunt, roles historically charged with the care of others (Gilligan, 1982/2009). The Overdue Attendee is positioned to screen as evidence of her belongingness to the dominant cultural group—white Australian, English-speaking women.

The Obligated Attendee is positioned to screen to protect and preserve the service for other deserving women (i.e., English-speaking Australian women). Some feminist perspectives would counter that these positionings reinforce dominant ideologies and power dynamics that repress women (Dodds, 2000). For example, by subject positions being void of choice, it appears that others (e.g., family and friends, health profession, government), maintain control over women and their bodies. As such, a woman who chooses not to screen destabilises gendered norms by putting herself before others. This, in part, may help to explain why women who do not engage in cervical/breast screening have been regarded as lazy, irrational, and irresponsible (i.e., by health professionals, other women; Seaman, Dzidic, Breen et al., 2018; Todorova et al., 2006). This narrative, which negatively labels women for exercising bodily autonomy that does not align with dominant ideologies, is well established—voluntarily childfree women report that their decision is seen by others as an act of social deviance (Doyle et al., 2012), while research on female bodybuilders concluded that their bodies are stigmatised for disregarding aesthetics traditionally accepted as feminine (Shilling & Bunsell, 2009). Media depictions of screening mammography may contribute to this narrative; one which limits women’s ability to have choice and autonomy over their body. Positioning women as screening for others could be viewed as decision-making in the context of relationships that are central and valuable to them (Dodds, 2000). However, women were *predominantly* positioned in relation to caring for others, which may limit their opportunity to make an informed choice.

Finally, I also critique instances which appear to facilitate a diversity of choice but do not realistically provide it. For example, when the Vulnerable Attendee was positioned to advocate for/attend 3D screening, choice was seemingly provided and encouraged. However, this choice also represents a new way in which technology is positioned as the expert of bodily surveillance. In this way, the media continues to valorise screening technology as the "answer" to reducing breast cancer deaths (Lupton, 1994), which further reinforces medical dominance and closes opportunities for a woman to choose not to engage in screening mammography. Continued critical examination of the choices presented to women, and the ideologies underpinning them, is warranted.

5.6.2 Limitations and Future Directions

As subject positions are situated in particular socio-cultural, historical, and political periods, the findings may not be applicable to other countries or time periods. However, for countries with national screening mammography programs and/or located within Western health models, the findings of this study may be useful as a basis for future work exploring "ways of being" made available by discourse in the context of screening mammography. In addition, I chose to only analyse the transcripts of television broadcasts to honour our focus on text-based discourse and ensure that the data remained manageable for in-depth analysis. In so doing, my analyses may have neglected important visual information. Future research could incorporate both verbal and visual analysis in their explorations of breast cancer discourse in the media, perhaps adapting multimodal critical discourse analysis techniques as Gibson et al. (2015) did in their analysis of Australian breast cancer websites. Future investigations should also seek to explore women's responses to media representations, so we may better understand how the media is drawn upon to construct and take-up subject positions in the screening mammography context (McGannon et al., 2016).

5.6.3 Conclusion

By analysing Australian television mass media representations of screening mammography, I identified three subject positions available to women—the Vulnerable Attendee, the Overdue Attendee, and the Obligated Attendee. Inherent in all subject positions is an expectation that a woman will engage in screening mammography; she is presumed to be an attendee and is positioned to screen for the benefit of others. These findings showcase how pertinent it is that researchers continue to analyse how mass media presents screening mammography. Such efforts may further illuminate unsettling practices and help to facilitate experiences where women regard screening as a choice.

Chapter 6: The Role of Discourse in Shared Decision-Making Practices in Screening Mammography: A Qualitative Study with Australian GPs

6.1 Chapter Overview

In this chapter I present the final study conducted in the research project, a critical analysis of the discourses GPs draw on when discussing screening mammography. The unpublished manuscript complements the findings of Study 2 and 3, presented in Chapters 4 and 5, by exploring the socio-cultural influences on GPs communication of screening mammography (via discourse), and critically examining how opportunities for women to make an informed decision are facilitated or restricted. The unpublished manuscript provides a strong rationale for examining GPs' communication, a summary of methodology, presents identified discourses, and highlights the implications for shared decision-making during the clinical encounter. I conclude the chapter with several recommendations to challenge current shared decision-making practices. These suggestions contribute to the recommendations for clinical practice made in Chapter 7.

6.2 Abstract

In this study I explored the discourses GPs draw upon when discussing screening mammography, and critically considered how such discourses facilitate or restrict opportunities for women to make an informed choice via shared decision-making practices. I conducted 12 face-to-face and/or telephone interviews with Australian GPs, and analysed the transcripts using FDA. I identified six discourses—Science, Government, Risk, Public Health, Professional Responsibility, and Paternalism—that indicate GPs recommendations, and shared decision-making practices, are governed by more than scientific evidence alone. GPs drew upon discourses that normalised the medicalisation of women's bodies (Science,

Government, Risk, Professional Responsibility, and Paternalism), which in turn lessened the need for shared decision-making. In addition, GPs drew on other discourses (Public Health, Professional Responsibility) to highlight the barriers they experience during the clinical encounter that inhibit them from engaging in shared decision-making. These discourses normalise screening for women aged 50-74 years, which underscores why they may be provided with fewer opportunities to engage in shared decision-making than women aged 40-49 years or 75 years and over. I provide several recommendations to challenge the normalisation of screening and reduce barriers experienced by GPs—clearer policy around shared decision-making in the breast screening-context, educational interventions, and changes to workplace practices.

6.3 Introduction

Screening mammography are X-rays of asymptomatic women's breast performed in the aim of detecting breast cancer (BreastScreen Australia Evaluation Taskforce, 2009). Biennial mammograms are considered the most effective method of breast cancer detection for average-risk women (Mandelblatt et al., 2016). However, the utility of population wide biennial screening is debated (Mandelblatt et al., 2016; Nelson et al., 2016; Welch & Passow, 2016). Concern is expressed for the benefit/harm ratio posed to asymptomatic women (Welch & Passow, 2016). Benefits include increased treatment options from early diagnosis and a reduction in breast cancer mortality by approximately 20% (Myers et al., 2015). However, this figure is debated due to advances in treatment options and screening technology that have decreased the advantage early detection once provided (Mandelblatt et al., 2016). Potential harms include overdiagnosis (the detection of cancers that, in the absence of screening, would not have been detected in the patient's lifetime), false positives and negatives that have been associated with psychological harm (i.e., anxiety and false reassurance), radiation, and pain from the mammogram (Myers et al., 2015; Sui, 2016).

Despite the contention regarding the benefit/harm ratio of screening mammography, research shows that women overestimate the benefits and underestimate the harms (Collins et al., 2010; Domenighetti et al, 2003; Seaman, Dzidic, Castell et al., 2018). A systematic review of women's knowledge of screening mammography demonstrated that women's awareness of harms such as false results varied considerably, while topics such as overdiagnosis, cessation ages, and mortality reduction were poorly understood (Seaman, Dzidic, Castell et al., 2018). Within medical contexts, informed consent is a legal and ethical obligation of GPs and stipulates that GPs disclose all relevant information to them (e.g., nature of procedure, benefits/harms, alternate options), assess a patient's capacity to make a decision, and support voluntary decision-making (Royal Australian College of General practitioners [RACGP], 2018).

Within breast screening, attempts are being made to support informed decision-making—decision aids are providing women with evidence-based information about the benefits and harms of screening (to the best estimate of the time), leading to an increase in the number of women making informed decisions (Hersch et al., 2017). However, decision aids are criticised for neglecting socio-cultural influences on decision-making and oversimplifying individuals as rational healthcare consumers (Stefanek, 2011; Vahabi & Gastaldo, 2003). In response, efforts are being made to renegotiate culturally embedded workings of power through the promotion of shared decision-making. Shared decision-making invites patients to the decision-making process—they are presented information about benefits and harms, alternate options (including not screening), encouraged to ask questions, and assisted in making a decision aligning with their values (DuBenske et al., 2017; Hersch et al., 2017). Public support for shared decision-making is reported—most Canadian adults surveyed preferred to be consulted on their health care preferences and be offered choice (Levinson et al., 2005), while 42-46% of Australian and Swiss women sampled preferred to take an active role in their breast screening decision-making (Chamot et al., 2004; Davey et al., 2005; Nekhlyudov et al., 2005). However, shared decision-making seldom occurs in practice—Fowler et al.'s (2013) research indicates that less than half of women in their sample (39.5%) were consulted on their preferences, while 45.6% of women reported that providers did not explain breast screening as a choice.

GPs report numerous difficulties when attempting to engage in shared decision-making, including the limited time allocated with patients (Dunn et al., 2001; Joseph-Williams et al., 2014), feeling uncertain of their ability to convey information accurately due to debated evidence (Dunn et al., 2001; Griffiths et al., 2005; Siedlikowski et al., 2018), and conflicting personal prioritisation of ethical principles (Parker et al., 2015b, 2015c; Parker & Carter, 2016). For example, one study suggested that Australian health experts (practitioners, program managers, advocates, researchers, and policy makers) who prioritised autonomy advocated for providing comprehensive information to women, while experts who prioritised delivering benefit advocated for the provision of limited information to ensure women were not discouraged to attend (Parker et al., 2015b). In another study, Parker and Carter (2016) identified that some experts may feel a sense of moral obligation to continue supporting breast screening programs, even in the face of uncertain evidence, based on their understanding that breast screening programs have contributed to better breast cancer treatment and care.

Few studies have explored the influence of psychological, social, and ethical factors on health experts' views on cancer screening (Parker & Carter, 2016). These studies have noted the influence of normative pressures upon health experts screening views and referrals, including the health expert's speciality (e.g., obstetrician-gynaecologists had higher mammography referral rates than other specialties; Bekker et al., 1999; Livingston et al., 2007), fears about litigation (Chamot & Perneger, 2001), differing ethical and epistemological values (Parker et al., 2015b, 2015c; Parker & Carter, 2016) and responding to patients requests (Lostao et al., 2001); the socio-cultural, historical, and political discourses within health care contexts that work to constitute certain types of citizens (Crawford, 1980, Gibson et al., 2017; Lupton, 1993, 1997; Peterson, & Lupton, 1996) remain obscured. However, studies have indicated that some women engage in screening mammography due to a sense of moral obligation to others, and/or to be constructed as “good” citizens (McGannon et al., 2016; Willis, 2004; Seaman et al., 2020). Such discourses may limit opportunities for women to make an informed choice within the screening mammography context.

To my knowledge, the discourses that GPs draw on when discussing breast screening with their patients has not been explored. The study resonates with the work of Parker et al., (2015b, 2015c) and Parker and Carter (2016) in exploring socially embedded concepts in health expert’s communication of breast screening; however, it differs through the sole inclusion of GPs as health experts due to their identification as key sources of information for women (Allen et al., 2013; Seaman et al., 2020), a wider scope of socially embedded concepts (i.e., not only ethical concepts), and Foucauldian theoretical framework. Based on Foucault’s (1973) keen attention to power dynamics and assertion that discourse constitutes social life, his ideas are applicable in a context where individuals may be positioned to adopt health behaviours that are currently contentious, and where unequal power relationships exist (i.e., the clinical encounter; Lupton 1997). As such, in this study I seek to identify the discourses GPs draw upon when discussing screening mammography with patients and how these discourses influence the practice of shared decision-making and informed choice.

6.4 Method

6.4.1 Design

I used a qualitative design with semi-structured one-on-one, face-to-face or telephone interviews to explore the discourses GPs drew upon when discussing screening mammography with women. The decision to focus on discourse is supported by my social constructionist epistemological position and aligns with our choice of theoretical framework and analysis, Foucauldian discourse analysis (FDA). In alignment with social constructionism, Foucault (1973) rejects the idea of a true reality and highlights the role language and communication plays in constructing the self and world (Galbin, 2014). According to Foucault (1977), discourses create certain ways of understanding a phenomenon. Discourses are both productive and restrictive; they direct individuals to act and speak in ways that are constructed as socially acceptable for particular times and places (i.e., subject positions; Foucault, 1977). Adopting this perspective allowed the exploration of how the discourses used by GPs shaped their communication of screening mammography, the practice of shared decision-making, and thus opportunities for informed choice.

6.4.2 Participants

Convenience sampling was used to recruit English speaking GPs from Western Australia. GPs were targeted for this study as research indicates they are regarded as important sources of health and breast health information for women (Allen et al., 2013; Clarke et al., 2016; Hersch et al., 2013; Seaman et al., 2020 [Chapter 4]). Sample size was informed by data saturation, wherein recruitment/interviews stopped when no new ideas arose from the current data (Hodges, 2011). GPs were recruited from social media and magazine posts in various health professional groups, a presentation at BreastScreen WA’s monthly multi-disciplinary meeting, general medical practices, and snowballing. The final sample comprised 12 GPs (2 men and 10 women), meeting the recommendation of 12 by Braun et al. (2015; see Table 4). Eight participants were recruited from an email circulated to members of the RACGP specific interest group, Breast Medicine. Nine participants identified themselves as having potentially relevant health interests (i.e., in addition to their general practice), which included women's health (*n* = 3), breast cancer (*n* = 2), oncology (*n* = 1), preventative medicine (*n* = 1), and health screening (*n* = 1). All participants were familiar with BreastScreen Australia, the free national breast screening program offered to women aged 40 years and over, and aware that it specifically targets women aged 50-74 years of age for biennial screening.

Table 5. *Participant Demographics (N = 12)*

	N	**%**
Longest Place of Residency		
Australia	8	66.67
USA	1	8.33
Sri Lanka	1	8.33
United Kingdom	1	8.33
Singapore	1	8.33
Years of Practice as a Registered GP		
0-5	3	25
5-10	3	25
15-20	2	16.66
21-25	2	16.66
31-35	2	16.66
Age		
30-34	2	16.66
35-40	2	16.66
40-44	2	16.66
45-50	3	25
55-60	3	25

6.4.3 Interview Schedule

Literature was used to inform the semi-structured interview schedule, which was further refined by the research team. Questions were opened-ended; however, prompts were used to elicit further responses where necessary. Questions were categorised under eight headings: rapport building (e.g., "Could you tell me what motivated you to participate in this study?), knowledge of breast cancer/screening (e.g., Could you tell me about detection methods of breast cancer?), perceptions of BreastScreen Australia (e.g., What is your opinion on the service they provide?), perceptions of attenders/non-attenders of screening (e.g., How do you perceive women who engage in mammograms?), dialogue used during the medical encounter (e.g., Could you give me an example of the conversation you would have with a women aged 50 about the topic of breast health breast screening?), shared decision-making/informed consent (e.g., What does shared decision-making mean to you?), sources of mammography information (e.g., Where do you get information about screening mammography?), and summary questions (e.g., Is there anything you would like to add?).

6.4.4 Procedure

The research was approved by the Curtin University Human Research Ethics Committee (HRE2016-0214). Participants were provided with an information sheet, consent form and demographic questionnaire. Prior to commencing the interviews, participants were provided an opportunity to ask questions. Once satisfied, participants returned their signed consent forms and responded yes to the verbal request to turn on the voice recorder. Interviews ranged from 23.54 to 46.34 minutes (*M* = 30.26, *SD* = 7.83) and were conducted in GP’s offices (*n* = 1), cafes (*n* = 3), and via telephone (*n* = 8). Aligning with common practice for research involving health professionals (Biezen et al., 2018), all participants were provided with a $120 Myer Coles gift card upon completion (either as a physical copy or emailed depending on preference) as a thank you for their time. The audio recordings were transcribed verbatim and analysed after each interview to inform data saturation.

6.4.5 Data Analysis

FDA enables the deconstructing and questioning of everyday truths/practices associated with screening mammography and provides an understanding of GPs' behaviour as embedded within complex social contexts (Willig, 2013). There are multiple ways to conduct FDA and I decided to follow the six steps outlined by Willig (2013). In following Willig's (2013) steps, I used NVivo 12 qualitative data analysis software to code the data according to the steps.

In step one (*Discursive constructions*), I identified several ways in which the GP participants discussed screening mammography (e.g., one positioned screening as evidence-informed, while another positioned screening as fallible). In step two (*Discourses*), I explored what wider discourses the GP participants drew on when constructing screening mammography. During step three (*Action Orientation*), I explored what could be gained by constructing screening in particular ways located within particular discourses. In step four (*Positionings*), I sought to identify the subject positions made available to GPs, and when possible, their patients (i.e., women), when GP participants drew on each discourse. During step five (*Practice*), I considered what actions were considered legitimate within these subject positions for GPs. Finally, in step six (*Subjectivity*), I explored what could be experienced in the context of shared decision-making from these positions for GPs and women. After analysing the transcripts individually, I opened step-orientated nodes to identify patterns across the data. During this process preliminary discourses were identified; although invited to, no participants provided feedback on preliminary findings. The preliminary findings were discussed by the research team (which included a clinical psychology doctoral student and three researchers with substantial qualitative experience) until six discourses were agreed upon. In aligning with the aims of FDA, I chose to present the findings according to the identified discourses, and where possible, commented on the available subject positions for GPs. To further ensure quality in my analysis, alongside analyst triangulation, and respondent validation, I produced a comprehensive audit trail that includes all steps of data analysis and electronic copies of notes from meetings/drafts of findings.

6.5 Findings and Interpretations

In this section, I present the six discourses upon which the GP participants drew when discussing screening mammography. These were discourses of Science, Government, Risk, Public Health, Professional Responsibility, and Paternalism. In each discourse, I highlight how screening mammography is constructed and demonstrate how GP participants draw upon discourses to legitimatise certain messages.

6.5.1 Scientific

All GP participants drew on a discourse of Science to construct screening mammography as an evidence-informed practice and to encourage women to act in accordance with screening guidelines. These guidelines recommend that women aged 40-49 years make a decision to screen based on personal choice and current knowledge, women aged 50-74 years screen biennially, and that women aged 75 years and over talk to their GP about continuing or ceasing screening (BreastScreen Australia, 2015). The following quotes are examples of what participant GPs said they would say to their patients when discussing screening mammography:

> Well, I basically based it on the evidence and that's what I've been told. So, I stick to that and hopefully, I give that information out to women to say that, this is what science shows.
>
> [*If in a conversation with a woman aged over 75 years*], I tell them that there's probably not a lot of evidence for say breast screening or mammogram would benefit them in terms of detecting or making any changes to their morbidity or mortality. Although I wouldn't really say that morbidity and mortality. I would say that there’s probably not a lot of evidence for screening in that age group over 74.
>
> [*If in a conversation with a woman aged 50-74 years who does not want to screen*], Sometimes I'll say medically speaking, this is what we should do as well as what's advised, but I understand if you don’t want to do it for a few weeks. If it’s not the right time to do it. Everything is negotiable.

Each quote demonstrates how Science is drawn upon as a discursive resource to align women’s behaviours with the guidelines. Specifically, Science is discursively drawn upon through the terms “science shows,” “evidence,” and “medically speaking.” The terms illustrate the authority and legitimacy of science in Western societies. Their use by participant GPs suggest that GPs are governed by the scientific paradigm and endorse evidence-based practice; thus making available the subject position of the Governed GP. However, their function, to enforce guidelines, suggest that GPs may be governed by a more complex relationship between science and governments as discussed within the discourse titled government. Further to this, patients of Governed GPs are also in effect then governed, with this being particularly evident when a patient’s actions deviate from the guidelines. For example, in the final quote, the choice to not attend screening from a woman aged 50-74 years is reframed by the GP as attendance at a later date under a guise of negotiation.

6.5.2 Government

All GP participants constructed screening mammography as a practice endorsed within a discourse of Government. Government encapsulates governing bodies cited by GP participants which included BreastScreen Australia and Cancer Australia; national government agencies, and the RACGP, Australia’s largest professional general practice organisation. Like Science, the Government discourse was drawn upon as a discursive resource to encourage women to follow guidelines regarding screening mammography. However, unlike Science, it was not used as a discursive resource during clinical encounters; instead, it was used to justify GPs’ recommendations and practices during the interview. For example, one GP said:

> I think there's a bit of disincentive for GPs to do informed consent to that degree in the 50 to 74-year-old range because it's recommended. So, the fact that Australian guidelines, and I think United States guidelines for that matter, say we recommend breast screening aged 50 to 74. We just recommend it, suggest it, and if they say yes or no and we often move on from there. For the less than 50 [years] or certainly less than 40 [years] and then the over 74 [years], I would be much more likely to have a more detailed conversation. But no, I think the fact that the guidelines, so frankly say it, having a long conversation about something that’s recommended by the Australian Government or whatever authority it is, that seems like a very big waste of time.

In this quote, the GP draws on the Australian Government as a discursive resource to justify why they would not have a “detailed” conversation with women aged 50-74 years of age about screening mammography. Prior to this comment, the GP recognised a “detailed” conversation as, discussing “the benefits, the risks, the alternatives, including nothing. That’s proper informed consent.” In this way, the Australian Government, and their guidelines, serve as a disincentive for GPs to facilitate an informed decision with their patients aged 50-74 years.

Why, in the healthcare context, the Australian Government holds authority was outlined when another participant said, “They [the Australian Government] wouldn't provide the service free if there wasn’t good evidence for it” and when another participant said:

> I feel like you people know about mammograms. So, when you're giving them a form to have one that they know what they’re in for. But maybe, on reflection, they wouldn't necessarily know the false positive and false negative rate. But I mean if I equated it to a PSA [prostate specific antigen] test, I spent a lot of time talking [with patients] about all of the positive and negatives of having the PSA. But with a mammogram, probably because it’s on the [Australian] Government-funded list, I wouldn't be having so much of a discussion about it [possibility of false results]. I would feel like it [screening mammography] was more supported with science even though may be in some ways it’s not.

Here, participants dually draw on the construction of screening mammography as an evidence-informed practice within a discourse of Science and Government. Both Science and Government discourses are privileged; each is seen to establish, deliver, and enforce “truths.” In the first quote, the government is cast as an enforcer of science, which suggests that ultimately, the GP is governed by a Scientific discourse. However, in the second quote, the government is cast as a distinct authority figure. For this GP, the funding from the government is seen as more powerful than their own questioning of evidence supporting the screening mammography program and as such, they recommend screening to women. This GP also compares breast screening with PSA testing. A Medicare rebate is available for men once every 12 months for PSA testing but there is no government-funded population-wide screening program implemented in Australia (Brett, 2011). Hence, this relatively minor difference in funding appears to underpin the GP's very different approach to informed choice, rendering women as having less autonomy over their bodies than men. The privileging of the Government discourse over the Scientific discourse challenges the positioning of GPs as governed predominantly by the Scientific discourse, and instead suggests GPs may at times, be more strongly positioned by Government discourses: "guidelines are guidelines. I just follow them."

While government guidelines appear as a disincentive in facilitating an informed choice for women aged 50-74 years, they appear to enable this opportunity for women aged 40-50 years or 75 years and over:

> [*If in a conversation with a woman aged over 75 years*], I would have a more open discussion about the benefits of mammogram, I guess. That if you're welcome to have them, please [do]. But I guess it depends on the health of the woman. So rather than discussing in an absolute, 'you really should have the mammogram,' it would be more about let's look at your risk factors and, and try and find something early if something does turn up.
>
> [*If in a conversation with a woman aged 40-50 years*], I also do talk to them usually a little bit in that 40 to 50 age group particularly, or [in] pre-menopause, about the risk of false positives and that it doesn't detect all breast cancers and it can sometimes detect things that will turn out to be okay and can cause more angst because you need more investigations.

6.5.3 Risk

In contrast to the construction of screening mammography as an evidence-informed practice, most GP participants also constructed screening as a practice that may miss detecting breast cancer, either as a consequence of false negatives or because breast cancer may develop between screens. In this way, the GPs drew upon a discourse of Risk to construct the mammography machine as fallible and women's body as *still* risky, post-screen. This elevation of risk enabled them to encourage their patients to engage in breast self-examinations or breast awareness:

> I try and mention about mammograms can miss a certain percentage of cancers, particularly as a lot of women say, 'Ah, that's fine.' I say, 'Have you done a recent breast examination?' And they say, 'Ah, no it's fine. I had my screen a month ago.' So I try and emphasise it's still important in between to be breast aware and breast self-examine.

> So, again, as I keep mentioning, that they need to be aware that screening is, if they don't have symptoms, even if they've had a mammogram six months ago. And they've felt a new breast lump, they should get that checked out and not be reassured that the mammogram was normal six months ago. So that's quite important.

However, breast awareness and self-examination practices are not considered to reduce breast cancer related mortality (McCready et al., 2005). Several participants acknowledged this:

> I ask her whether she checks her breasts herself, and I do also let her know that doing regular breast examination does not actually decrease her risk of dying from breast cancer, so I do not make that a burden that she has to carry, but something that I just say do not ignore her breasts.

> The other thing that I also tell them is yes, it's important for them to do a self-breast examination. But the evidence of picking up any early breast cancer is very low. So,

> it’s actually category C [“body of evidence provides some support for recommendation(s) but care should be taken in its application,” National Health and Medical Research Council, 2009, p. 16] in terms of evidence. So, it’s not the most reliable, but it encourages awareness of their breasts.

In these quotes, the GPs construct breast self-examination as a practice that has little life-saving benefits within a Scientific discourse, which prompts participants to discuss the evidence associated and instead recommend general awareness of the breasts. However, breast awareness is also a contentious practice. For example, some research suggests that more treatment options are available due to early detection of breast cancer, and that the process enables women to experience bodily control (McCready et al., 2005), however other research acknowledges the uncertainty regarding whether the benefits of breast awareness outweigh the harms. Potential harms include an increase in the presentation of the “worried well” at medical centres (Thornton & Pillarisetti, 2008) and the reinforcement of discourses that position health as an individual responsibility, which for some women, can leave them vulnerable to blame if they developed disease (Kline, 1999). Despite this uncertainty, both participants still recommended breast-awareness to their patients. For some GPs, their recommendation aligned with McCready et al.’s (2005) research, and breast awareness was recommended in attempts to empower their patients, “So I do put a lot of that responsibility and try to empower the patient to understand that they play a very important role in the screening [via breast awareness] and not to just rely on the imaging” while others discussed no reasoning.

6.5.4 Public Health

GP participants identified time as a limited and valuable resource and highlighted how short consultation times hindered their capacity to facilitate an informed decision with their patient; a comment echoed by GPs in previous research (Dunn et al., 2001; Elwyn & Edwards, 2014). For example, the following two quotes from the same GP showcase what they described their “ideal” consultation regarding breast screening would look like, versus their reality:

> I guess I'd just be saying look, this is the program that exists in Australia, and this is the current guideline in terms of when we start it, how frequent and the reasons for that. And then asking the patient if they’ve heard of it, what they understand about it, whether they’re willing to be a participant in it, and if not, why? And if they are doing it, just making sure they understand what it entails, and also that they understand what it’s for.

> I think where we fall down is, we generally don’t go through all this information; we just tell patients to go start their screening. But I think where we fall down in particular is if there is an abnormality, what the next step is going to be. And I guess just letting patients know, often we find something incidental; this is all practical information, in reality, we’re time-poor, and we generally just don’t have time to go through everything in so much detail. That’s partly our fault, but it’s also partly that a patient might come in and book a 15-minute appointment, and have a whole array of things to discuss, and you’ve just got to do the best you can, and get through what you can, in terms of information. You could sit there and go through all this stuff, but then you might also fail to address some really important issues in that consult. So, I’m sort of giving you, in an ideal world what we would do.

Here, the GP outlines that their ability to facilitate an informed decision for screening is limited by time. They construct themselves as partly responsible for this; however, by drawing upon a Public Health discourse, they reposition the inability to facilitate an informed choice as a consequence of their professional responsibility to deliver the most benefit possible within available resources. A conversation that facilitates an informed-choice for screening is then constructed as less important than addressing the immediate concerns of the patient. For this GP participant, the competing needs are resolved by condensing the message about screening to one which tells patients to “go start their screening.” This GP also partly constructs the patient as a barrier to facilitating an informed choice through their decision to book a short consultation when having a number of presenting problems. The construction of the patient as a barrier to facilitating an informed choice serves to reposition the responsibility to become informed back onto the patient, who *should* book longer appointments. I argue this reflects the ambiguity regarding where the responsibility lies for an individual to become informed.

Time, as a constraint to facilitating informed decision-making, is again outlined by another GP, wherein they state what informed consent means to them and how associated information is discussed during the clinical encounter, “Well, informed consent, just basically means, does the patient understand what it means if they have a negative results. Or worse there's a positive result. Sometimes they might not know what the consequences are of a positive result” and:

> I mean, to be very honest, I don’t have a lot of those conversations when it comes to breast screening. I think if something's flagged I’ll tell them at that point, I’d have a more detailed conversation. I don't think, it’s very hard when you’re trying to jump on everything else that a GP has to do. Try to cram it like a proper…. You feel bad when patients are waiting and, trying to balance, making sure you give the patient in front of you enough the time as well as trying to juggle walk in patients in the waiting room. I think it’s maybe time for me.

For this GP participant, ensuring *all* patients receive care is paramount which limits opportunities for screening-related patients to make an informed-choice regarding their participation in screening. As such, it appears that GPs, even if wanting to support an informed choice for their patients, are governed and limited by their professional responsibilities within a discourse of Public Health.

6.5.5 Professional Responsibility

Most GP participants held varying opinions on the necessity of informed consent broadly, and in relation to screening mammography, as seen in the following quotes from three different participants: "I think it's our role as a health professional to inform people of risks and benefits and encourage them to do it [screening mammography] if they think it's the appropriate thing to do" and:

> I don't think GPs get involved with informed consent. It should be, like, if I refer a patient for an MRI or a CT or ultrasound guided biopsy of the breast lump, it's the person doing the procedures' role… If we're just strictly speaking, just talking about mammogram itself. Yes, usually I might talk them through about what to expect, and how accessible is it.

> I guess it's a graded issue in GP practice. So, there are some things that are required. Like, if you sent someone for a blood test and you gave them the form and they go up to have the blood done, it's kind of implied that they know that there's a little needle stick. And there's a very small risks associated. So, you don't really go over that. And then it goes all the way up to skin excisions and things that are much more invasive where you would have a written consent. I think mammogram probably falls quite low in that list of consent…. I feel like, people know about mammograms. So, when you're giving them a form to have one that they know what they're in for.

Here, the second and third GP participants are seen to draw on a discourse of Professional Responsibility to displace the responsibility of supporting their patient make an informed decision about screening away from them. Although, the second GP participant does note they would discuss some procedural related information (i.e., “what to expect, and how accessible is it”). Another GP stated, “Informed consent, I guess varies enormously doctor to doctor.” Such discrepancies are problematic in that they increase the possibility for inequality in practice, whereby some patients will be provided an opportunity for informed decision-making, while others will not.

For several GP participants, the responsibility to inform women about screening mammography was “displaced” to mass media. For example:

> Most of them [women] they are really quite aware of it because there’s pretty good campaigns on the television, on the radio and even on shopping centres. So, they’re usually quite knowledgeable already, usually already kind of thinking of it and I just need to say so why not do it, it’s quite easy and it’s free and usually they’ll just do it anyway.

> Well, my impression is they [women] do understand what they’re about. Because it’s in the news a lot. Breast cancers in the news a lot. Nowadays, they probably go online to have a look at it. So, my impression is that their understanding is good. I think they understand what a mammogram involves because they all talk about, they don’t want to have the pain and all that. I think they understand that it can pick up cancer before it’s a lump.

Here, GP participants mitigate the responsibility of information sharing away from themselves/the clinical encounter and re-distribute it to women via their consumption of mass media. In this way, an assumption that all women have access to mass media is being made, women are constructed as already knowledgeable, and screening mammography is constructed as almost an “every-day” and normal medical practice. However, this is problematic for several reasons. First, as reported in Seaman et al. (2020), women tend to overestimate the benefits of screening and underestimate the harms. Second, mass media has been identified as creating enthusiasm for mammography screening through misinformation or ambiguous/overly positive communication (Gigerenzer, 2014; Jones, 2004; Jørgensen & Gøtzsche, 2006) and, as reported in Seaman et al. (2020) and Chapter 5, mass media communicates to women that engaging in screening mammography is not something requiring choice, instead it is something in which women aged 40 and over will engage.

6.5.6 Paternalism

From within a discourse of Paternalism, screening mammography was constructed as a complicated, but necessary practice wherein women were afforded different amounts of information and agency. When constructed as complicated, women who were assumed to be educated were provided opportunities to engage in informed decision-making:

> I mean, to me, informed consent is strictly speaking, the patient knows the pros and cons of whatever they’re going to do. And the pros and cons means they know all the alternatives as well and the alternatives, you try to give it to them, you try to give everything. But some patients can’t take that level of information and usually they just rely on your recommendation and usually you say okay, in this case, if you screen, you pick up early disease and maybe you won’t die. If you don’t screen, you might pick it up later, and you might die. So, to keep things simple, it all depends on the patient. But, if they are a highly-educated person, you can give them all the information and they can make the decision themselves.

Here, this GP constructs “educated” women as capable of understanding information about screening, thus capable of informed decision-making. They continue to draw on a Paternalistic discourse to construct other women as incapable of understanding and as such, in need of care. Such assumptions contribute to the development of informed choice as a bounded and privileged practice; afforded only to women deemed educated. By assuming a woman’s educational status, the GP’s paternalistic practice may be understood as dominated by out-dated ideologies in medical care (Lupton, 1994). Paternalism in healthcare is problematic as it serves to maintain inequality and has been found to be ill-founded. For example, a narrative synthesis of studies examining the impact of shared decision-making interventions on disadvantaged groups, concluded that these interventions benefited disadvantaged groups more than groups with higher socioeconomic, literacy, and education status (Durand et al., 2014). Benefit was seen as increased knowledge, informed decision-making, participation in decision-making and reduced decisional conflict. Such results challenge GPs assumptions that shared decision-making is not appropriate for individuals with low health literacy and reinforces the importance of not bounding informed choice to “educated” women (Durand et al., 2014; Leng et al., 2017).

However, the privileging of educated women from within a Paternalistic discourse appears to compete with the assumption that educated women are women who look after their health, therefore already *know* to screen. For example, one GP participant noted “They [educated women] do know that they should get screened for breast cancer. Especially because I work in an area where it’s quite a high socioeconomic and so they're all mostly well-educated and they’re all aware of health education,” while another GP participant stated,

> I’ve worked in probably quite more upper middle-class areas. So, the uptake rate is actually quite high. So, it’s actually been really easy for me. So, I’ve haven't even had

> to say, “Oh you have to go and have it.” So, [it] depends on where you practice and I think where you actually work.

The participants likely draw on the construction of screening as an evidence-informed practice to create a parallel between participating in screening and being well-educated. The educated woman is then positioned as an “easy” patient because they follow screening guidelines.

Women who screen were also constructed as being responsible for their health, while women who do not screen could be regarded as careless or reckless: “A woman who does attend screening probably looks after her health and takes up all the opportunities that are for preventive health” and “If you’re not going to be a risk taker, then it makes good sense to go and do a screening test, because doing the screening test, it is like looking left and right before you cross the road.” The moralisation of screening attendance appears linked to the construction of breast cancer as common, “breast cancer – it's such a common thing amongst women” and “It [reminders from BreastScreen Australia] just reinforces the fact that breast cancer is common and why I want her to go for a screen” and, the construction of screening mammography as a “job” women are expected to perform: “I think they [women] just hear about it. It’s on women's lists of things they meant to do.” In this way, women are positioned as vulnerable to developing breast cancer, and expected to partake in screening in an effort to reduce their risk of dying from breast cancer. Ultimately, these constructions add to rhetoric normalising (and praising) the medicalisation of women’s bodies and may contribute to the acceptance of paternalistic practice in relation to informed decision-making in the breast screening context.

6.6 Discussion

In this article, I identified six discourses GPs draw upon when discussing screening mammography—Science, Government, Risk, Gender, Public Health, Professional Responsibility, and Paternalism. The findings echo the work of Parker et al. (2015b, 2105b) and Parker and Carter (2016) by showing that GPs reasoning and communication of screening is influenced by more than scientific evidence alone. In addition, I have identified how socio-cultural factors, in the form of discourses, work to either facilitate or restrict opportunities for women to make an informed decision during the clinical encounter.

I have shown that GPs understand screening mammography as an evidence-based practice for women aged 50-74 years of age and draw on Science as a discursive resource during the clinical encounter to encourage women to follow evidence-informed, government-endorsed guidelines. For GPs, and women aged 50-74 years, this discourse legitimises screening as the only viable option, and enables GPs to re-frame women’s desires to not attend into an expectation that they will attend at a later date. This narrowing of options (re)produces the subject position of the Overdue Attendee identified in Chapter 5, wherein women who do not attend screening are assumed to be encountering barriers to attendance rather than expressing their legitimate desire. In addition, evidence-informed government guidelines serve as disincentives for GPs to engage in shared decision-making during the clinical encounter with women aged 50-74 years, but facilitate this process with women aged 40-49 years and women aged 75 and over.

I have also shown that GPs draw on a discourse of Professional Responsibility to displace and/or minimise the importance of facilitating informed choice during the clinical encounter. On one level, this may be understood as role ambiguity and necessitate that governing bodies produce clearer guidelines with direct reference to screening mammography; currently the RACGP (2018) does provide guidance for GPs regarding patient education but this guidance is applicable broadly for preventive health. However, adopting a more critical stance, the minimisation and displacement of facilitating an informed choice may be better understood as products medicalising women's bodies. The process of medicalisation displaces women as the experts of their own body and leads women and health professionals to believe that the body cannot be appropriately managed without medical intervention (Griffiths et al., 2010; McHugh & Chrisler, 2015). In turn, this enforces a norm that women will *want* to and *should* screen.

On several occasions, I identified GPs drawing on discourses that acted to normalise screening mammography. For example, GPs drew from discourses of Risk and Paternalism to normalise women monitoring their breasts (i.e., breast awareness or screening), and construct screening as practice engaged in by the safe, educated, and compliant woman. Similar subject positions have been identified in Seaman et al. (2020) and Study 3 (Chapter 5), wherein women are constructed as responsible and "good" women for reducing their risk of breast cancer via screening and for complying with their GP's recommendations to screen. The dichotomy of easy and hard patients speaks to the Judicious Woman, a subject position identified in Seaman et al. (2020) wherein women who choose to not attend screening are framed as acting in opposition and resistance to higher authority for exercising autonomy over their bodies. These constructions of women arise from health rhetoric like Healthism and the New Public Health that moralise the maintenance of health and associate it with characteristics such as self-control and rationality (Crawford, 1980, Peterson & Lupton, 1996), and from problematic gender narratives that position screening mammography as inherent to womanhood. Research suggests that risk-reducing citizens are valued because of their efforts to maintain their capacity to contribute to society (Peterson & Lupton, 1996), or for women specifically, to continue to serve (i.e., care for) others (Chapter 5; Gilligan, 1982/2009). I critically question if this normalisation further governs GPs to endorse paternalistic messages (e.g., “just start screening”) that limit women’s opportunities to make an informed decision about screening.

I have also shown that some GPs desire to facilitate an informed choice during the clinical encounter for all women, however, feel unable to do so due to short consultation times. In these cases, GPs appear to prioritise the principle of maximising benefits (i.e., addressing patients presenting concerns and seeing as many patients as possible) as more important than respecting autonomy. This finding supports the work of Parker et al. (2015b, 2015b) who identified that the way health experts communicate screening is dependent upon their understanding and prioritisation of ethical values. However, my analysis understands, that for some GPs, this prioritisation could also be a by-product of environmental constraints rather than their own values/desires.

6.6.1 Implications for Clinical Practice that Promote Informed Choice

Women aged 40-49 years and 75 years and over are provided more opportunities to engage in shared decision-making about screening mammography than women aged 50-74 years. This is because for women aged 50-74 years, screening mammography is constructed as the legitimate breast health practice. I have identified that this could mean a woman’s desire to not attend may be reframed as attendance at a later date or lead a GP to perceive her as a difficult patient. If a woman was to attend screening, she may be constructed as a safe, risk-reducing, educated, and easy patient. If a woman was assumed to be educated, she may experience a greater pressure to attend because she is considered to have the capacity to evaluate the evidence and expected to conclude that the national screening mammography program is beneficial. However, women assumed to be “uneducated” are likely barred from shared decision-making processes to, what appears to be, attempts to reduce the possibility of a “wrong” choice. Overall, the identified discourses contribute to the normalisation of screening mammography for women aged 50-74 years, and without appropriate intervention, limit opportunities for women to legitimately choose to not screen, construct women who do not want to screen as “difficult”, and may bar some women (i.e., “uneducated” women) from opportunities to make an informed choice.

Key socio-cultural factors that appear to restrict opportunities for women aged 50-74 years to make an informed choice, and that may be amenable to intervention, are GPs positioning to *just* follow guidelines, role ambiguities, tensions related to time constraints, and the normalisation of screening as embedded in a broader narrative of medicalising women’s bodies. First, informed choice should be promoted more strongly (e.g., with direct relevance to screening mammography) within relevant policy (e.g., government-informed and/or professional body guidelines). Doing so may begin to challenge the normalisation of screening for women aged 50-74 years and lead to a greater value being placed on promoting autonomy within the breast screening context by GPs. For example, the RACGP (2018) guidelines for preventative activities in general practice includes the following statement, “The decision to start screening mammogram should be an individual one. This is especially for women aged <50” (pp. 110). While the statement does support individualised choices, it offers little guidance regarding the GP’s role during the process, and may benefit from greater emphasis on what it means for women to make an informed choice, clarifying who is responsible for assisting women in making an informed decision, and detailing how GPs can provide an autonomy-supporting environment for screening mammography specifically.

Ways in which GPs can provide an autonomy-supporting environment are well documented and emphasise the importance of informing women that they may decline the offer of screening and that further information should be made available to those who *want* it (Hersch et al., 2017; Seaman et al., 2020). In England, this approach is termed “consider an offer” and has been the basis for breast-screening communication since 2013 (Hersch et al., 2017). To my knowledge, the “consider an offer” approach is supported in the Australian literature (Entwistle et al., 2008; Hersch et al., 2017) but not yet adopted by policy. However, for women wanting further information, the approach may not alleviate the tensions experienced by GPs due to limited consultation times. In these instances, it may be worthwhile to direct women to at-home decision aids, which have shown to increase patients’ knowledge of screening mammography (Mathieu et al., 2007, 2010). However, this option negates women’s desire for discussing breast screening decisions with health professionals (Seaman et al., 2020; Toledo-Chávarri et al., 2016). Alternate approaches such as internet-based communication may be a viable solution in enabling women to follow-up directly with their GP, while also limiting time spent during consultations discussing such information. High acceptability of Internet-based communication on cancer screening was demonstrated by Cutrona et al. (2013) in their study of 438 American adults over the age of 40. However, to avoid overloading GPs, funding boards and workplaces would need to allocate time within schedules to respond to patient emails.

Furthermore, opportunities should be provided for practising GPs, in the form of supported professional development, or for medical students, as part of their educational studies, that illuminate past and ongoing medicalisation of women’s bodies, encourage reflection upon their ethical values in relation to the national screening mammography program, construct shared decision-making as an important tool that should be used with all women to support autonomy, and reduce paternalistic practice. It is possible that such educational intervention will lead GPs to question the appropriateness of forgoing assisting women aged 50-74 years to make an informed decision by triggering cognitive dissonance (Sukhera et al., 2018). Cognitive dissonance was triggered in GPs and nurses following a four-hour learning activity that focused on bringing implicit bias towards patients with mental health difficulties into awareness, fostering critical reflection, and enhancing conscious efforts to overcome biases (Sukhera et al., 2018). Participants reported that, over time, due to their conscious awareness of biases, they adopted more egalitarian and empathic behaviour towards patients with mental illness and highlighted the importance of the workplace being a safe and supporting space for behaviour change (Sukhera et al., 2018).

6.6.2 Limitations and Future Research Directions

The findings of this study should be considered in light of the study's context. For example, the study was conducted within a country that is dominated by Western models of health, has an established national screening mammography program, and provides Government funded primary medical care. While the findings may serve as a useful base for exploration in countries with similar health care systems, future research is needed to understand the discourses drawn upon by GPs within other socio-cultural contexts. It is also important to note that our sample was predominated by women, whereas women comprise only 47.1% of GPs who provide primary care in Australia (Department of Health, 2019). With patients preferring same-sex GPs when discussing gender-specific or psychosocial difficulties (Kerssens et al., 1997), it is possible that shared decision-making for breast screening may be different for women with male GPs, and as such future research should be conducted to explore this possibility. In addition, most GP participants held specific interests in breast medicine—eight GP participants were recruited from the RACGP Breast Medicine specific interest group and an additional GP reported interest in breast-related medicine/care. It is possible that the discourses drawn upon are a result of high familiarity with breast screening and/or do not adequately capture the experience of GPs more broadly. Finally, we join researchers such as Hersch et al. (2017) in suggesting that future research should further explore GPs current capability (i.e., skills) to support shared decision-making in the breast screening context and develop ways in which skill development could be supported (e.g., specific educational interventions).

6.6.3 Conclusion

By exploring the discourses that GPs draw upon when discussing screening mammography, I join researchers such as Parker et al. (2015b) and Parker and Carter (2016) in showcasing that GPs practice is influenced by more than scientific evidence alone, and that socio-cultural factors impact how GPs reason, judge, and communicate screening mammography. I identified several discourses that acted to normalise the medicalisation of women's bodies, and (re)produce subject positions for women which regard them as safe, responsible and compliant women when engaging in screening mammography. The normalisation of screening and associated subject positions were particularly problematic for women aged 50-74 years, or for women whose educational status was judged to be "uneducated." Women aged 50-75 years were, due to government guidelines, restricted in making an informed decision, while "uneducated" women were barred from the process in fears they may make the wrong choice. As such these women were provided fewer opportunities to engage in shared decision-making than women aged 40-49 and 75 and over. Further complicating this context, GPs also drew on discourses that showcased the tensions associated with shared decision-making during the clinical encounter, including limited time within the clinical encounter and ambiguity in their role to support shared decision-making. Informed by Foucault (1973), I see GPs practice as a product of past and current socio-cultural, historical and political discourses, and as such, I have suggested several interventions that aim to alter the environment in which GPs learn and practice within in efforts to facilitate shared decision-making opportunities for all women.

Chapter 7: Discussion

7.1 Chapter Overview

In this chapter, I first provide a review of my research objectives before synthesising the main findings from Chapters 3 to 6. In doing so, I show how my findings address the overall research objectives. Next, I discuss the implications of the findings for promoting informed choice through policy and practice. In discussing my implications for informed choice and recommendations for improved policy, practice, and communication, I incorporate the previously reviewed work of Foucault and feminist accounts of procedural autonomy to highlight the utility of my recommendations. I then discuss the strengths and limitations of the research overall and identify important areas of future research. Finally, I conclude the chapter by presenting my closing remarks.

7.2 Review of Thesis Objectives

Given the contention surrounding the ratio of benefits and harms posed to asymptomatic women participating in national screening mammography programs (Gøtzsche & Jørgensen, 2013; Pace & Keating, 2014), I support policy and practice shifts that aim to enhance the number of women making an informed decision before participating. As such, the present research initially sought to address gaps in the literature by conducting the first systematic review of women's knowledge of screening mammography (research objective 1) in the aim of providing recommendations for improved communication. Further to this, informed by the work of Foucault (i.e., discourse, power/knowledge and governmentality), and feminist accounts of procedural autonomy, I recognised that current policies and practices aiming to support women in making an informed choice (e.g., decision aids, shared decision-making within the clinical encounter, ambiguous policy) neglected the role of socio-cultural, historical, and political processes on women's decision making. Provided that research has demonstrated engagement in women’s screening programs (i.e., breast and cervical) is enmeshed with social and moral obligations (Howson, 1999; Willis, 2006), and that language is a powerful tool in which “way of beings” are made available, legitimised, and resisted (Burr; 2015; Foucault, 1972), an exploration of how “choice” is discursively constructed within screening mammography is important. An exploration of the discursive constructions of choice (research objective 2) enabled an identification of the subject positions made available to women, and critical consideration of whether they, and constituting discourses, were autonomy supportive or undermining (research objective 3). An exploration of the discursive construction of choice also enabled recommendations to be made that aim to improve policy, practice, and communication to support informed decision-making (research objective 4). The proposed changes recognise, rather than neglect, the influence of socio-cultural, historical, and political processes on women’s decision-making.

Using a sequential qualitative research design, this project comprised four studies—a systematic review of women’s knowledge of screening mammography (Study 1; Chapter 3); a FDA of women’s discourse that aimed to explore the subject positions made available within participants discourse and examine the implications to informed choice (Study 2; Chapter 4); a FDA of mass media that similarly aimed to identify subject positions made available to women and examine the implications to informed choice (Study 3; Chapter 5); and a FDA that aimed to identify the discourses GPs drew upon when discussing screening mammography and examine the influence on the practice of shared decision-making (Study 4; Chapter 6). Each study informed the next in expected ways (i.e., contributing to participant/data selection and addressing the overarching research aim) and unexpected ways (i.e., contributing to shifts in my conceptualisation of informed choice).

7.3 Summary of Major Findings

Through an exploration of the discursive construction of choice within screening mammography, the present research suggests that “choice” is not discursively made available within mass media, nor within most discourses used by women or GPs when discussing screening mammography. However, the present research did identify ways in which discourse, as used by women and health professionals, could be autonomy enhancing, thus facilitate opportunities for choice in the breast screening context. Further to this, the present research contributes to evidence that indicates women’s decision to engage in screening mammography is related to social and moral obligations (Griffiths et al. 2010; Willis, 2004), by identifying several moralised subject positions, and that women tend to overestimate the benefits of screening mammography and underestimate the harms (Chamot & Perneger, 2001; Domenighetti et al., 2003; Schwartz et al., 2004).

7.3.1 Study 1

Study 1 (Chapter 3) aimed to be the first systematic review of women’s knowledge of screening mammography conducted in the context of countries that are members of the ICSN-Breast Cancer Division and thus have a national screening mammography program. Systematically reviewing what women know about screening mammography was an important endeavour within the project because accurate knowledge of a procedure represents an important feature of making an informed decision—that women possess an accurate understanding of the benefits and harms of a procedure and are positioned within environments that support autonomous decision-making (as informed by feminist-procedural accounts of autonomy; Donchin, 1995; Stoljar, 2000). As such, the systematic review sought to explore women’s understanding of screening mammography.

The systematic review produced two major findings. The first finding broadly indicated that women underestimate the harms of screening mammography and overestimate the benefits. More specifically, the findings indicated that most women were aware of screening mammography, understand screening mammography to be a practice for asymptomatic women, and accurately regarded the risk of harm from screening mammography radiation as low. However, other areas of knowledge were more variable in terms of their response ranges. For example, I found large variability in women's awareness of the potential for false results, purpose of screening, and in their understanding of the age/frequency at which women are recommended to screen. Further to this, most women believed that there was no recommended age to cease screening mammography and overestimated the lifesaving benefits that screening mammography offers participants. Finally, in most studies, less than half of the women were aware of the concept of overdiagnosis and/or confused when the concept was presented. Overall, the findings indicate that women with access to a national screening mammography program tend to overestimate the benefits of screening and underestimate the harms. Therefore, it is possible that many women are not making an informed choice within these breast screening contexts.

The second finding of the systematic review demonstrated the variability, and ultimately ambiguity, regarding what women *should* know in order to make an informed choice. The ambiguity was reflected in the variations of topics/concepts included in the 11 studies that produced a knowledge score. Although the researchers of the 11 studies did not explain why certain topics were included/excluded in their measure, the differences may reflect concern and debate in clinical practice. Health experts have expressed concern that greater involvement of lay people in decision making for breast screening may exacerbate inequalities and ultimately discourage some women from screening (Blue Moon Research & Planning for the Australian Government Department of Health and Ageing, 2008; Hersch et al., 2017). The concern that greater involvement may discourage some women from screening has led some health experts to endorse less transparent communication in attempts to ensure participation rates in the national screening mammography program do not reduce (Parker at al., 2015c). As such, variability in topics/concepts within screening mammography knowledge measures may reflect the contention surrounding what is important/necessary for women to know to make an informed choice, but also optimise maximum population uptake of national screening programs.

The variability demonstrated in the systematic review, and debates within the wider literature, in relation to what women should know when making a decision about screening mammography, led me to question the utility of a universal definition of informed choice. Standardised definitions of informed choice that are underpinned by a need to ensure people possess adequate knowledge of a procedure/process have been recognised as problematic for several reasons—the uncertainty inherent in medical information, differing consumer preferences for information, and differing opinions on the best way for knowledge to be understood (e.g., should people know specific facts/figures or just the "gist"; Ghanouni et al., 2016). In hindsight, the questioning of the utility of a universal definition of informed choice represents the first point in my thesis where my conceptualisation of informed choice shifted. I came to understand an informed choice as a decision made in the context of *opportunities* to accurately understand the benefits and harms of a procedure and within an environment that supports an autonomous decision. Although I did not express this definition explicitly in subsequent studies, I adopted this framework when proposing a shared decision-making framework in Study 2 (Chapter 4) and continue to do so now in Chapter 7. As such, the questioning of the utility of a universal definition of informed choice, which is a perspective that privileges opportunities for knowledge, rather than the possession of knowledge, was an important finding that shaped my thinking, and contributes to proposed shared decision-making frameworks (see Study 2; Chapter 4).

7.3.2 Study 2

In Study 2 (Chapter 4), I identified three subject positions that are made available in women's discourse when discussing screening mammography—the Responsible Woman, who is a woman who attends screening mammography to reduce her likelihood of dying from breast cancer, the Irresponsible Woman, who is a woman who does not engage in any risk-reducing practices; and the Judicious Woman, who is a woman who engages in alternate risk-reducing practices.

Study 2 (Chapter 4) identified that all women were located within a society pervaded by a discourse of risk. Further to this, all participants within this study recognised the inherent riskiness of their female body and as such, all attempted in one way or another, to reduce their risk of developing and/or dying from breast cancer. This meant that, although women's behaviours differed (i.e., engaging in screening, not engaging in screening, engaging in exercise, eating healthily), all women acted to reproduce dominant ideas within a risk society—that health represents the choices of individuals and that risk-reduction is an important part of good citizenship (Crawford, 1980). As such, women who engaged in risk-reducing actions were deemed responsible, while women who took no action to reduce their riskiness were regarded as irresponsible. Further to this, the need to act responsibly (i.e., engage in risk-reducing behaviours, particularly screening mammography) appeared linked to notions of "good" femininity. For example, the Irresponsible Woman was in part constructed through a Parental Discourse that was used to question her identity as a good mother for seemingly risking her ability to engage in the responsibilities of motherhood. As such, women's decision to engage in screening mammography may be impacted by gender norms—consistent with prior work (Gibson et al., 2017), health management is indeed also a project of femininity.

Although all participants acted to reduce their risk of dying from breast cancer, through the discourses of the Responsible Woman and the Judicious Woman, it was clear that engaging in screening mammography was the most "correct" or legitimate form of risk reduction within this space. For example, the act of participating in screening mammography was identified as a practice of the Responsible Woman, while engaging in other risk-reducing behaviours (e.g., maintaining a healthy weight and diet), but not participating in screening mammography, were identified as practices of the Judicious Woman—the self-identified rebel. Through the Judicious Woman's awareness that her behaviour may be regarded as deviant, it is clear that women are aware of and, through their discourse, perpetuate norms about breast health—that women should engage in screening mammography.

Within this study, the privileging of screening mammography was constituted through Expert and Paternalistic discourses used by participants occupying the Responsible Woman subject position. For example, participants within this position regarded the mammography machine as the expert of bodily surveillance, thus displacing themselves as their own body's expert. The privileging of technology as experts of the body is consistent with prior work that has demonstrated women give more credence to the screening mammography machine in detecting breast cancer than they ascribe to themselves (Griffiths et al., 2010; Lupton, 1992). Participants occupying the subject position of the Responsible Woman also drew on a Parental Discourse to characterise GPs/the government as stern but caring parents who encouraged compliance with screening. This finding resonates with research that suggests health authorities reinforce the values of healthism and technological consumption (McGannon et al., 2016; Peterson & Lupton 1996). As such, through Expert and Paternalistic discourses, embedded within a wider discourse of Risk, engagement in screening mammography was constituted as the most legitimate way to reduce the risk of dying from breast cancer, thus enabling women to occupy the Responsible Woman subject position.

Although screening mammography was constituted the most legitimate breast health behaviour, space was created to engage in alternate risk-reducing behaviour and avoid identification with the Irresponsible Woman subject position. For example, women occupying the subject position of a Judicious Woman drew on an Expert Discourse to displace the mammography machine as the expert of their body, and instead used the discourse to reframe themselves as the expert. Women occupying the subject position of the Judicious Woman also drew on a discourse of Risk in several ways—they engaged in greater individualised assessment of breast cancer risk than the Responsible Woman and drew on risk discourses to challenge the construction of screening mammography as a helpful practice (as constituted by the Responsible Woman). They instead constructed screening as a potentially hazardous practice (e.g., likely to cause harm to the breast through radiation). By displacing the screening mammography machine as the expert of bodily surveillance/privileging the self and engaging in individualised risk-assessment (including assessing risk imposed by the mammography machine), women created space not to participate in screening mammography and instead engaged in alternate risk-reducing behaviours—engaging in physical activity and eating healthily. Although these techniques represent ways in which screening mammography may be decentred as the most “correct” practice within breast health, thus enhance the availability of other risk-reducing behaviours (i.e., choice), they may also be problematic—by reinforcing discourses of individual responsibility and perpetuating the presence of breast cancer/screening misconceptions. Later within this chapter, I discuss how these implications to clinical policy, practice, and communication could be managed in greater depth.

Overall, I conclude from Study 2 (Chapter 4) that, within women's discourse, choice to engage in alternate risk-reducing behaviours is limited. Women's discourse reproduced dominant ideas about risk—that individuals should engage in risk-reducing behaviours, which serves to either undermine or facilitate autonomy. At this stage, no breast health action is privileged above another; however, to abstain from any risk-reducing behaviours may lead to derogatory labels. For women, gender norms, perpetuated by a Parental discourse, act to reinforce the dichotomy of responsibility and irresponsibility associated with health management. Expert discourses can be used to undermine autonomy—when they privilege the mammography machine as the expert of the body, or enhance autonomy—when they privilege the self as the expert of the body. When explicitly drawn upon, a discourse of Risk can be autonomy enhancing—it enables individualised risk assessment to occur, thus makes available a wider array of acceptable health actions. Finally, when used to characterise others as more powerful (i.e., GPs/the government), a Paternalistic Discourse may be autonomy undermining, in terms of inducing compliance with expert recommendations.

Another key finding of this study is the variability documented in experiences of, and desires for, shared decision-making during clinical encounters with GPs. For example, some participants occupying the subject position of the Responsible Woman preferred their GP to be direct in recommending whether or not they should screen, while others preferred to be actively engaged in the decision with their GP. Women occupying the subject position of the Judicious Woman more commonly reported feeling pressured by their GPs and government communications (i.e., invitations or reminder letters) to participate in screening mammography. Further to this, they reported a lack of opportunity to engage with GPs in a conversation about screening. The variability in desire for, and experiences of, shared decision-making in the clinical context reported in this research is consistent with the wider literature (Chamot et al., 2004; Davey et al., 2005; Nekhlyudov et al., 2005).

7.3.3 Study 3

In Study 3 (Chapter 5), I identified three subject positions made available to women through mass media (Australian television news channels and National /state newspapers) between 2017 and 2019—the Vulnerable Attendee, the Overdue Attendee, and the Obligated Attendee. The subject positions were not bounded and women could be located within one or all simultaneously. Inherent in all subject positions was an assumption that women 40 years and over would engage in screening mammography. As such, mass media refrained from discursively constructing participation in the national screening mammography program as a choice.

Consistent with the findings of Study 2 (Chapter 4), women's bodies were constructed as perpetually at risk of developing/dying from breast cancer due to their femaleness. As such, the subject position of the Vulnerable Attendee was made available through a discourse of Risk. The analysed media appeared to privilege medical technology in the management of breast cancer risk—specifically constructing 3D mammography as superior to 2D mammography. When discussing 3D mammography, mass media positioned women as at risk of "missing out" on the technology due to government restrictions, and as such, encouraged them to lobby for access. The encouragement of women to access 3D mammography represents an example of false choice—in each option (either 2D or 3D mammography), medical technology is privileged as the expert of women's bodies and, as such, represents the continued valorisation of medical technology as the answer to breast cancer (Lupton, 1994).

Mass media also drew upon Scientific and Risk discourses concurrently to constitute the subject position of the Overdue Attendee—a woman not yet attending screening, however, once barriers are removed, would participate in screening. The mass media drew on a Scientific discourse to legitimise their claims that screening mammography reduces the risk of dying from breast cancer. As such, the media constructed women who screen as rational healthcare consumers. A rational healthcare consumer is a woman who adheres to Western medical knowledge (the dominant framework in Australia), and acts to mitigate their risky body. All women were assumed to be rational healthcare consumers, and as such, those not currently participating in the national screening program were characterised as experiencing individual (i.e., inaccurate risk perceptions), structural (i.e., busy schedules), and/or cultural (e.g., modesty) barriers. Further to this, mass media particularly focused on problematising the non-attendance of women from culturally and linguistically diverse backgrounds. The focus on women from culturally and linguistically diverse backgrounds highlights the dominance of Western medical models and serves to marginalise breast health practices that do not rely on screening mammography (e.g., maintaining a healthy weight and diet, limiting alcohol consumption, breast awareness). As such, the rational Australian healthcare consumer is a woman who screens, or who intends to screen.

Through the use of a Nationalist discourse, the Australian breast screening program was constructed as a valuable and expensive resource that is under threat from non-Australian women and/or women who do not honour their national responsibility to participate. By constructing the program as a valuable and expensive resource, women were positioned to feel grateful for the government’s investment of the taxpayer’s dollars towards saving women’s lives. As such, consistent with the findings of Study 2 (Chapter 4), women were positioned to view the government as caring, which, as demonstrated in Study 2, enhances compliance. In this way, the subject position of the Obligated Attendee was constituted; wherein women were encouraged to “take advantage” of the resource (i.e., screening mammography program) provided to them. Further to this, through the construction of the screening mammography program as under threat from non-Australian women and un-Australian women (i.e., those who do not participate in the national screening mammography program) within a Nationalist discourse, the Obligated Attendee was positioned to view only Australian women as “deserving” women. As such, the Obligated Attendee was positioned to screen in solidarity with other “deserving” women.

Overall, consistent with Study 2 (Chapter 4) and prior literature (Crawford, 1980; Peterson, 1997), the discourses drawn upon by mass media demonstrates the positioning of the writers within a risk society. In this way, the media produced perpetuates the construction of all women as risky due to their femaleness and assumed that women want to reduce their risk of dying from breast cancer. The positioning of mass media within Western medical models was illuminated when Scientific discourse was drawn upon to privilege medical technology in the management of breast cancer risk. As such, a woman attending screening mammography is constituted as a rational healthcare consumer. Women not attending screening were constructed as encountering personal, structural or cultural barriers. I argue that the use of Risk and Scientific Discourses, to construct all women as wanting to reduce their risk of dying from breast cancer, and that privileging medical technology in such risk mitigation, are autonomy undermining—where the only options available to women are to screen now, or to screen later. Arguably, the Nationalist discourse also undermines autonomy—by constructing the program as valuable, expensive, and under threat, women are positioned to feel cared for and lucky to possess the service (a service seemingly desired and threatened by non-Australian) women; thus, they should participate in the service.

In addition to the inherent assumption that all women *would* screen, I identified that within all subject positions, women were positioned to screen in servitude of others. Although I am informed by a procedural account of relational autonomy, and thus do not regard the positioning of women to screen in the context of relational ties as inherently autonomy undermining, I do problematise the notion of women being primarily positioned to screen in relation to caring for others. This is because a diversity of experiences, a key concept of my definition of informed choice, is absent. By not supporting a diversity of screening experiences and screening reasons, the only options available to women are ones in which others maintain control over their bodies. As such, gender norms (i.e., that women are charged with the care of others) are perpetuated, and in turn may marginalise the experiences of women whose actions do not conform with such norms. Research has demonstrated women who act in non-gender confirming ways risk being regarded as socially deviant and stigmatised (Doyle et al., 2012; Shilling & Bunsell, 2009).

7.3.4 Study 4

In Study 4 (Chapter 6), I identified six discourses that GPs draw upon when discussing screening mammography—Science, Government, Risk, Public Health, Professional Responsibility, and Paternalism. I identified that the opportunities to make an informed decision within the clinical encounter differ for women depending on their age and presumed educational status, and their GP's conceptualisation of their role with regards to informed decision-making in the breast screening context and prioritisation of ethical values under time constraints. Further to this, the findings support the work of Parker et al. (2015b, 2105b) and Parker and Carter (2016) by demonstrating that health expert's communication of screening mammography is shaped by more than scientific evidence alone.

For women aged 50-74 years of age, screening mammography was not discursively constructed as a choice by GPs in my study. Instead, GPs drew on discourses of Science and Government to construct screening mammography as an evidence-informed, government endorsed practice, thus establish its legitimacy. As such, there was an assumption, on the part of GPs, that women aged 50-74 years old would screen now, or at least, at a later date. This assumption reproduces the subject position of the Overdue Attendee identified in Study 3, wherein a women's attendance at screening is assumed to be the fault of barriers, without which, she will attend. Therefore, I argue that, within the clinical encounter, women aged 50-74 years may be provided limited opportunities to engage in informed decision-making. Thus, discourses of Science and Government, when used by the GP in a way that constructs screening as the legitimate breast health option, are autonomy undermining. In contrast, when GPs draw on discourses of Science and Government when discussing screening mammography with women aged 40-49 years or 75 years and over, they are autonomy enhancing. This is because GPs drew on discourses of Science and Government to characterise screening mammography as a practice that is less beneficial and not government endorsed for women aged 40-49 years or 75 years and over. As such, GPs reported having more detailed discussions with women aged 40-49 years and 75 years and over, and supporting women to continue screening if they desired. Therefore, women aged 40-49 years and 75 years and over are likely afforded more opportunities to engage in informed decision-making than women aged 50-74 years of age.

For women presumed to be highly educated, opportunities to engage in informed decision-making were superficially afforded. For example, while educated women were recognised as being able to understand the contentious literature surrounding screening mammography, thus be able to “digest” information from GPs, there was an assumption that, due to their educational status, they already knew they should be screening. As such, through a Paternalistic discourse, GPs constructed educated women as wanting to take care of their health and therefore as “easy” and responsible patients who will screen. The construction of educated women as health conscious, thus likely easy and responsible patients who will attend screening, resonates with the subject position of the Responsible Woman identified in Study 2 (Chapter 4)—inherent to both is an assumption that screening is part of good and responsible citizenship. Therefore, the assumption, that screening mammography is the “correct” breast health behaviour is perpetuated and “choice” for educated women is then limited. In contrast, women presumed to be “uneducated” were barred from informed decision-making in concern they may misunderstand the literature and make the “wrong” choice—not to attend screening. The attempted exclusion of some women from informed decision-making arguably perpetuates the misconception that the communication of screening harms is too complex (Entwistle, 2004). Overall, a Paternalistic discourse is autonomy undermining for all women and represents the presence of outdated medical ideologies (Lupton, 1994).

Further to this, I identified several discourses that, depending on their use, may be autonomy undermining or autonomy supportive. For example, GPs drew on a discourse of Professional Responsibility to either place or displace the role of supporting women to make an informed choice in the breast screening context, on to, or away from them. Concernedly, some GPs displaced the responsibility to assist women in making an informed choice to mass media—which my third study (Chapter 5), and the wider literature have demonstrated, may lead women to develop misconceptions about screening mammography (Gigerenzer, 2014; Jones, 2004; Jørgensen & Gøtzsche, 2004), and limit their experiences of screening mammography as a choice (see Chapter 5). Furthermore, one GP inferred displacing the responsibility of supporting their patients to make an informed choice to individuals conducting the procedure (e.g., employees of BreastScreen Australia). The displacement of responsibility to BreastScreen employees may limit women’s experience of choice in two ways—employees are financially incentivised to ensure women attend screening, while their physical presence and authority acts as means of persuasion in ensuring women commit to the screen (Arson et al., 2018).

Although some GPs did assume the responsibility to support women in making an informed choice, all described being unable to fully adopt the practice due to limited consultation times. These GPs drew on a discourse of Public Health to prioritise seeing as many patients as possible (i.e., delivery the most benefit) over supporting autonomy. My findings support the work of Parker et al. (2015a, 2015b) by also showing that health expert's communication of screenings mammography is influenced by the prioritisation of ethical values. Although none of my GP participants described instances when they were able to draw on a discourse of Public Health in an autonomy enhancing way, the findings show that some GPs did desire to support autonomy but are limited by structural barriers.

Finally, GPs drew on a discourse of Risk to construct the mammography machine as potentially fallible, and women's bodies as still risky post-screen. As such, through a discourse of Risk, women are encouraged to engage in breast awareness. In one way, the Risk Discourse is autonomy undermining; inherent in the aforementioned construction is the presumption that women engage in screening prior to engaging in breast awareness. Thus, when used in this way, a Risk discourse normalised the practice of screening mammography. However, when constructing the mammography machine as potentially fallible and recommending breast awareness, the machine is displaced as the expert of the body, and instead women are privileged as the "final" experts. Thus, when a Risk discourse is used to displace the mammography machine as the expert of bodily surveillance, it is autonomy enhancing. However, as stated previously in this chapter, the privileging of the self as the bodily expert does (re)produce a discourse of individual responsibility, which may place more responsibility on women to manage their health.

Overall, when used in autonomy undermining ways, the discourses of Science, Government, Public Health, Professional Responsibility, and Paternalism, act to normalise screening mammography as the legitimate breast health practice. As such, women who attend screening are regarded as educated, "easy" and responsible patients, while conversely, women who do not attend may be regarded as difficult and/or uneducated. These constructions resonate with those identified in Study 2 (Chapter 4)—the Responsible and

Irresponsible Woman—and thus suggest that women and GPs are influenced by shared socio-cultural, historical, and political processes that make available certain ways of being.

7.4 Implications for Informed Choice: Policy, Practice and Communication

Overall, the present findings suggest that, for many women, an informed choice within the breast screening context is not available, and that screening mammography is the most “correct” breast health behaviour. Guided by a feminist-normative framework, I regard the limited opportunity to make an informed choice within the breast screening context as morally unacceptable (Dodds, 2003; Ells, 2003). My stance is compounded by the reality that the benefit and harm ratio posed to asymptomatic women (i.e., who are at average risk) is contended in the literature (Gøtzsche & Jørgensen, 2013), and my own findings that have highlighted the value-laden ways of being within the breast screening context (e.g., Responsible versus Irresponsible Woman, and easy or difficult patients). Value-laden ways of being that privilege screening mammography above other breast health behaviours are problematic for several reasons—they may limit the awareness/acceptability of actual risk-reducing practices (e.g., maintaining a healthy weight and diet, limiting alcohol consumption, Cancer Australia, 2018), reinforce the dominance of Western medical models that perpetuate the normalisation of medicalising women’s bodies (i.e., through their privileging of medical technology), and may perpetuate discourses of blame. As such, I make several recommendations for policy, practice and communication that include discursively and conceptually reframing informed consent to informed choice, the adoption of the “consider an offer” approach to screening mammography policy and practice, and the implementation of shared decision-making in clinical practice that uses discourse, identified by the present research, as autonomy enhancing.

7.4.1 Reframing Informed Consent to Informed Choice

While it is beyond the scope of the present research to offer a definitive reconceptualised version of informed choice, I propose several key features that should be included in the reconstruction of informed consent to informed choice. First, I argue that informed consent should be discursively reframed to informed choice in bioethics language and associated policy and practice (i.e., clinical encounters). Foucault (1972) regarded discourse as a way in which social life is constituted and, in taking this perspective, the term informed consent constitutes compliance. Inherent in the term informed *consent* is an expectation that the focus of the consent (i.e., screening mammography), is a forgone conclusion. Instead, the term informed *choice* implies that there is, in fact a decision to be made. Therefore, the discursive reframing of informed consent to informed choice in relation to screening mammography arguably facilitates the perception that participation in the national screening mammography program is a choice, rather than an expectation. Further to this, the act of discursively reframing informed consent to informed choice can be regarded as an act that attempts to dismantle power relations. For example, in the screening mammography context, GPs and/or BreastScreen staff are privileged as powerful consent seekers (i.e., by medical expertise and social norms that prescribe screening as a moral obligation for women), while women are consent givers; positioned within a medicalised context that may regard their bodily expertise as less. However, when using the term informed choice, neither the roles of consent seeker or giver are made available, and instead, efforts to facilitate collaborative and informed decision-making are discursively made available.

Second, the definition of informed choice should take into consideration how shared and unique socio-cultural, historical, and political processes impact women's willingness to participate in the national breast screening program (Ells, 2003; Miner, 2017). In the current research, several shared socio-cultural processes were identified as positioning women to screen—a risk society, healthism rhetoric, and gendered expectations (i.e., that contributed to the favourable labelling of women who attended screening and unfavourable labelling of women who did not), the privileging of Western medical models/medical technology, and power dynamics between women and the Government/GP. In addition, the present research also identified that women's experience of choice, or degree of choice afforded to them, in screening mammography differed due to their perceived belongingness to culturally and linguistically diverse groups (Study 3; Chapter 5) and perceived educational status (Study 4; Chapter 6). In this way, the findings of the present research challenge the voluntariness presented within Beauchamp and Childress' (2001) definition of informed consent—that an individual's decision is not controlled by others. A woman's decision to engage in screening mammography does in fact appear controlled by others—the degree to which, socio-culturally, screening is even regarded as a choice, and other's willingness to facilitate/foster decision-making (i.e., GPs during the clinical encounter). As such, I join others in arguing that a definition of informed choice should actively recognise that women's experience of choice is influenced by both shared socio-cultural processes, and individualised factors (e.g., social class, race, educational status; Ells, 2003; Miner, 2017). By recognising that women's experience of choice in the breast screening context is shaped by socio-cultural processes, people (i.e., policymakers, health professionals, and producers of mass media) are provided an opportunity to critically question if they act to reinforce such processes or inequities at the expense of limiting choice.

Third, a definition of informed choice should reject the notion of the liberal self within definitions of informed consent and instead understand that people exist, thus engage in decision-making, within social relations. For example, the findings of the present research and prior work, indicate that the decision to participate in screening mammography can be experienced as a social obligation (Griffiths et al., 2010; Willis, 2004). By recognising that decision-making occurs in the context of social relations it enables an opportunity to critically question what social ties are privileged in the context of screening mammography. Findings from Study 2 (Chapter 4) and Study 3 (Chapter 5) indicate that women's role as caregivers is privileged within the screening mammography context—women are positioned to screen so they may remain healthy and continue to care for others. Aligning with my procedural feminist framework, the reinforcement of gender norms is not disconcerting, but instead it is the privileging of this norm that is problematic as it limits the ways of being made available to women within the breast screening context. Participation in screening mammography should not be narrowly experienced as something a woman can do for others—this, according to feminist perspectives, negates her intrinsic value as a person (Friedman, 2003).

Finally, a definition of informed choice should support people in either accepting or rejecting all options presented. Within this framework rejections should be more than "allowed" but regarded as a valid choice (Handa & Sharpe, 2015). In doing so, the variability identified in the present research (i.e., in preferences for information on screening mammography, involvement in shared decision-making and chosen breast health behaviours) would be respected. A respect for diversity would contribute to dissolution of value-laden labels associated with women who do not attend screening mammography, potentially reduce paternalistic practice of GPs during clinical encounters, and enable the constitution of different subject positions within this context—perhaps subject positions that explicitly and largely value actions that reduce the risk of developing breast cancer (i.e., maintaining a healthy diet and weight and limiting alcohol consumption; Cancer Australia, 2018). Although the promotion of subject positions that promote risk-reducing actions (i.e., maintaining a healthy diet and weight and limiting alcohol consumption) requires further critical reflection as such 'ways of being' also serve to proliferate health moralisation. Nonetheless by expanding the range of legitimised breast health options available to women (i.e., rather than narrowly focusing on screening mammography), a diversity of experiences is supported, and thus informed decision-making becomes an individualised process.

Overall, a Foucauldian and feminist-informed reconceptualisation of informed consent (i.e., informed choice) recognises the power of discourse, argues for a discursive shift from informed consent to informed choice, and rejects the voluntariness embedded within bioethical autonomy. As such, informed choice instead understands autonomy as constrained by options made available in the shared socio-cultural environment/belongingness to social categories and recognises women as existing within social relations. Therefore, a Foucauldian and feminist-informed reconceptualisation of informed consent sees the importance of identifying privileged and negated social ties, seeks to support a diversity of experiences, and thus regards decision-making in the screening mammography context as an individualised process (Ells, 2003; Miner, 2017). It is important to discursively and conceptually reframe informed consent to informed choice because, in doing so, a need to create/adopt aligning policy and practice is fostered.

7.4.1.1 The “consider an offer” approach

The “consider an offer” approach represents a communication strategy that could be adopted within Australian breast screening policy and practice that better supports informed choice than current policy and practice. For example, current BreastScreen Australia policy seeks to ensure all participants provide informed consent by aiming to “improve program communications on the potential benefits and harms of screening” (https://wiki.cancer.org.au/policy/Breast_cancer/Policy_priorities). This policy oversimplifies the decision-making process by constructing an informed decision as one that can be made with the possession of adequate knowledge. Common communication strategies used by health experts (i.e., clinicians, programme managers, policymakers, advocates, and researchers) when discussing screening tests (including breast screening) are also problematic and include approaches characterised by the message of “be screened” or “be screened and here’s why” (Entwistle et al., 2008; Parker et al., 2015b). These approaches persuade people to screen by emphasising the benefits, de-emphasising potential harms, and by neglecting to convey that declining the offer to screen is a reasonable option. Other common approaches are characterised by providing people with less guidance, more information, and requiring the participant to make the final decision; such approaches are often identified in the literature as “analyse and choose” or “screening is available, please consider whether it is right for you” (Entwistle et al., 2008; Parker et al., 2015b). Reduced guidance may be experienced by some patients as abandonment (Lupton, 1997a).

In contrast, the “consider an offer” approach is founded upon a respect for autonomy and includes an open explanation and discussion on recommendations provided, encourages and facilitates the individual to assess the offer (i.e., in terms of trustworthiness of information and personal relevance of the offer), assists with further information/option seeking if the individual requests, and highlights that declining the offer/recommendation is a reasonable decision (Entwistle et al., 2008; Hersch et al., 2017). The “consider an offer” approach supports informed choice in several ways—by discursively reframing screening mammography as a choice through the terms *consider* and *offer*, enabling decision-making to occur in the context of at least one social relation (i.e., collaboratively with the GP), and by supporting a diversity of experiences through the recognition that declining an offer to screen is a reasonable option. However, the ‘consider an offer’ approach neglects explicit consideration of the influence of socio-cultural, historical, and political process on women’s choice to engage in screening mammography. Nonetheless the adoption of the approach in policy and practice may still be worthwhile. For example, in the breast screening context, by acknowledging the choice to screen or not screen as equally reasonable decisions (i.e., for women with average risk of developing breast cancer), blame-worthy discourses and value laden subject positions associated with women who do not screen may be de-legitimised. Further to this, the positioning of the machine as the expert of bodily surveillance may also be altered, and thus other breast health behaviours (i.e., maintaining a healthy weight and diet, reducing alcohol consumption) may be regarded as equally valuable and taken up.

However, potential costs of adopting the “consider an offer” approach within the breast screening context should also be considered. It could be argued that the “consider an offer” approach continues to perpetuate discourses of individual responsibility wherein individuals are charged with the maintenance of their health and may be judged through their decisions (now with more potential options to consider rather than screening mammography). It is hoped that decision-making could occur in collaboration with GPs, and thus the responsibility of health is shared. However, I recognise that GPs are constrained by time (Dunn et al., 2001; Joseph-Williams et al., 2014; Study 4 [Chapter 6]), and that some women may not engage with a GP upon the invitation of screening mammography. As such, BreastScreen Australia could explicitly adopt the “consider an offer” approach within their marketing material (e.g., campaigns, website, information sheets, and screening invitations). Within these materials, there could be an emphasis on the notion that *all* decisions are reasonable responses to the offer of breast screening. In this way, women who do not consult with their GP may feel supported in their decision-making by another (e.g., government).

Although, the “consider an offer” approach does not fully encapsulate all elements of an informed choice, it does represent a more suitable strategy for communication than current options in policy. Further to this, the approach is likely feasible in an Australian context as other similar countries (i.e., Westernised medical model, national screening program) have adopted this policy—since 2013 the “consider an offer” approach has been used as the framework for communication in England’s breast screening program (Hersch et al., 2017).

Finally, it is important to note that some current Australian policies/guidelines do include elements of the “consider an offer” approach—the RACGP (2018) indicates to GPs that the decision to participate in breast screening is an individual one and encourages GPs to provide information on individual risk and consider patient preferences. Within these practice guidelines, informed decision-making in the breast screening context is at least constructed as an individualised process, which indicates that a diversity of decisions should be equally respected. Such guidelines can be further enriched, rather than discarded, with the incorporation of a “consider an offer” approach (e.g., discursive shifts to informed choice).

7.4.1.2 Shared decision-making in the clinical encounter

Shared decision-making within the clinical encounter represents a process and context in which the “consider an offer” approach can be embedded. In practice, the “consider an offer” approach may adopt Elwyn’s et al. (2012) three-step model which focuses on introducing choice, describing the options, and supporting deliberation. By introducing choice, noting all options, and supporting deliberation, the model has the capacity to facilitate an informed choice—choice is discursively and legitimately evident (i.e., in the second step wherein all options are presented) and an opportunity to make a collaborative decision is afforded. Within Elwyn’s et al. (2012) model, the individual is encouraged to be an active member of the process. However, it is important to consider that not all patients desire this level of involvement (Say et al., 2006). A potential concern is that the proposed model in itself suggests to women that they should be active decision-makers which could marginalise some women’s desire to adopt more passive decision-making styles wherein GPs lead/make the decisions (Say et al., 2006). Lupton (1997) cautions against elevating one type of patient over the other—the active consumer versus the dependent patient—as doing so may undermine the beneficial aspects of traditional doctor-patient relationships. As such, GPs must enact flexibility and be attuned to their patients' requests for more or less involvement; decisions that could be equally respected. Again, the variability in patient desire for involvement highlights the need to adopt a somewhat individualised framework for informed decision-making. Nonetheless, broader frameworks and principles can still be applied; however, they must include "decision points" which enable different processes to be engaged.

To further align Elwyn et al.'s (2012) three step model with informed choice, GPs should also be attentive to the shared socio-cultural, historical, and political processes, and individualised factors, that influence women's willingness to participate in screening mammography, and be willing to address them in conversations with patients (Ells, 2003; Miner, 2017). For example, GPs should be attentive to statements from patients that indicate they feel they *should* be screening. In such instances, GPs could help patients to critically reflect upon and understand their reasons for feeling this way. In doing so, the GP is facilitating the patient to make a decision that aligns with their authentic self; a marker of autonomous decision-making according to feminist-procedural theories of autonomy (Friedman, 2003). In this process, the GP does not aim to identify right or wrong reasons for screening, but instead aims to help the patient critically reflect upon their decision, understand how it came to be, and feel satisfied with their desire (i.e., not alienated by their decision following critical self-reflection; Christman, 1991). In addition, such a conversation also creates an opportunity for GPs to attend to misconceptions about the efficacy, benefits, and harms of screening that may be informing women's decisions to screen or not screen (as seen in Study 2; Chapter 4). However, attentiveness to unique and shared socio-cultural processes that influence women's decisions may first require assisting GPs to engage in critical reflection on their own, and society's values towards screening mammography.

Critical self-reflection, on the part of the GP is needed as the process of facilitating their patients' autonomy first requires insight in their own motives for recommendations, an understanding of the socio-cultural processes within the breast screening context, and recognition of one's own positioning within the context (i.e., as medical professionals with a Western medical model; Atkins, 2006). As illuminated in Study 3 (Chapter 4), self-reflection may lead a GP to question how uncritically they are willing to *just follow guidelines*. By recognising one's own desires and how they have been shaped by the socio-cultural context, one is then better positioned to identify such processes within others discourse, and ask associated questions that promote reflection upon them. The development of GPs critical self-reflection skills represents a direction for future research and is discussed in greater depth in the relevant section later in this chapter.

Further to this, shared decision-making that supports an informed choice could be enhanced by the inclusion of discourses identified by the present research as autonomy enhancing. In drawing from Foucault's (1972) ideas (i.e., the power of discourse), the inclusion of autonomy enhancing discourses during the clinical encounter could provide an avenue in which subject positions that do not privilege screening mammography as the most correct breast health behaviour may be made available. In Table 5, I provide examples of how autonomy limiting statements could be rephrased to autonomy enhancing statements for women aged 50-74 years of age and thus better support women in making an informed choice regarding their participation in BreastScreen Australia. The discourses presented in Table 5 do not represent all autonomy limiting discourses identified in the research; instead, only those identified as both autonomy limiting and enhancing, and those most likely used in shared decision-making with patients, are included.

Table 6. *Examples of how Autonomy Limiting Statements could be rephrased to Autonomy Enhancing Statements during the Clinical Encounter for Women 50-74 Years of Age.*

Key Discourse	**Example Statements that could be used by the GP**	
	Autonomy Limiting	Autonomy Enhancing
Risk	“Attending screening mammography could save your life”	“There are several ways in which you can reduce your risk of developing/dying from breast cancer” [Provide information on screening mammography, breast awareness and lifestyle modifications*]
Expert	“The mammography machine enables us to see inside your breast and detect breast cancer before you could feel or notice any changes”	“While the mammography machine may enable us to see inside your breast on a cellular level, many breast cancers are also detected by women themselves through breast awareness…” [Provide education on breast awareness*].
Scientific	“Evidence shows that biennial screening mammography is recommend for women aged 50-74 years”	“Current evidence suggests that biennial screening mammography benefits women aged 50-74 years. This currently means… [Provide current evidence on efficacy**. If asked for more information, provide data on the benefit/harm ratio*]

Government	"The government guidelines recommend that you screen every 2 years"	"Government guidelines recommend that you consider the invitation to screen every 2 years"

Notes. *Information could be provided to women in the form of educational handouts deemed to be unbiased by independent reviewers. **Assuming screening mammography offers a 15% reduction in the relative breast cancer-specific mortality; over a 10-year period, 1 in every 2000 women will avoid dying through detection of breast cancer via mammography (Gøtzsche & Jørgensen, 2013).

7.5 Strengths, Limitations, and Future Research

A detailed description of the strengths, limitations, and future research directions of each of the four studies are provided in Chapters 3, 4, 5, and 6. As such, this section briefly summarises key strengths and limitations of each study before providing a synthesised summary of important future research directions. The strengths of Study 1 (Chapter 3), the systematic review, lie in the methodological rigour imposed, which included the publication of a PROPSERO systematic review protocol; involvement of an independent reviewer to assess study eligibility, quality appraisals, and data extraction; and efforts to reduce heterogeneity between studies (e.g., sample age, ICSN countries). Key limitations of Study 1 included the variability in methods that assessed women's knowledge, the limited detail about design provided in several studies and the exclusion of non-English articles.

The key strengths of Studies 2, 3, and 4 (Chapters 4, 5, and 6), that all drew on the same methodological approach (FDA), included the clear documentation of each study's/participants' context as conducted within a Western understanding of health and screening and a country with a national screening program. Given that discourse is located within a particular socio-cultural time and place (Foucault, 1972), the recognition of context is important to note that findings may not be applicable to other countries or time periods. Another key strength of Studies 2, 3, and 4 (Chapters 4, 5, and 6), included the quality assurance processes associated with data analysis. These included producing a comprehensive audit trial and engaging in triangulation with the research team (i.e., a doctoral student, three researchers with extensive qualitative research experience, and for Study 2 (Chapter 4), also a research-active breast cancer surgeon). In addition, for Studies 2 and 4 (Chapter 4 and 6), which involved research participations, I invited all participants to provide feedback on preliminary data interpretations—of which two participants provided feedback indicating satisfaction with my interpretations associated with Study 2. Finally, a key strength of Study 3 (Chapter 5), similar to Study 1 (Chapter 3), lies in the methodological rigour imposed regarding data collection—refined inclusion/exclusion criteria, systematic search within three databases, and involvement of a co-author to review study eligibility.

Key limitations of Studies 2 and 4 (Chapter 4 and 6), include the overrepresentation of several characteristics compared to the national population. This included a higher percentage of women who screen biennially and a higher percentage of female GPs, respectively. In addition, almost half of the participants in Study 2 (Chapter 4) reported having a previous role in the healthcare sector, while the majority of participants in Study 4 (Chapter 6) reported belonging to groups associated with, or having an interest in, breast-related medicine and care. However, this may represent an expected bias associated with voluntary participation—participants engage in research that aligns with their own interest. Finally, a key limitation associated with Study 4 (Chapter 6) was the exclusion of visual media from the analysis in my attempt to ensure the data remained manageable for in-depth analysis.

The recommendations for future research provided here either stem directly from addressing the aforementioned limitations within each study or pertain to supporting the application of clinical recommendations made earlier in the chapter. Therefore, in aligning with the recognition that the findings of my study are bound within a Western understanding of health and screening and a country with national screening programs, future research should explore how choice is constructed within other socio-cultural contexts. Exploration of choice, and associated subject positions, outside of the current socio-cultural context is important as it may help to identify differing needs, desires, and preferences for people from different socio-cultural contexts who are now residing in Australia. To address sampling bias, wherein certain characteristics may be overrepresented, future research may benefit from engaging in purposive sampling. This is particularly important when engaging with GPs in relation to discussions on women's health as research shows patients prefer same-sex clinicians (Kerssens et al., 1997). As such, the experiences of female patients discussing screening with male GPs may be different. Finally, in light of my exclusion of visual media, it may be worthwhile to incorporate both textual and visual materials in future analysis of media to ensure that any key meanings were not missed. Future work of this type may consider using multimodal critical discourse analysis, as Gibson et al. (2015) did in their critical analysis of breast cancer websites.

I suggest several future research recommendations, underpinned by efforts to further the clinical recommendations made, and to extend research aiming to support women in making an informed choice. For example, I advocate for the development of a psychometrically validated and culturally appropriate measure of knowledge regarding screening mammography. Notwithstanding my support for a conceptualisation of informed choice that privileges opportunities for knowledge rather than the possession of knowledge, a measure of knowledge would be valuable in assessing whether or not educational tools/resources (e.g., websites, pamphlets) are providing standardised, evidence-based, and current information to women and health professionals. As such, rather than acting as a tool that is administered to women and serves to categorise them as adequately knowledgeable or not, the measures act as a checklist to monitor if women are being provided an opportunity to access current and evidence-based information in an accessible way. However, within my suggestion, I recognise the tension within clinical practice and research literature regarding what information is deemed important for women to know (Ghanouni et al., 2016). As such, the measure should be developed in collaboration with past literature, policy makers, health experts, and women. Future research could utilise the methodology of citizens' jury; a deliberate method in which the public's opinion is surveyed (Paul et al., 2008). This will enable representation of the varied viewpoints within the community and facilitate a democratic solution regarding what information is important to support an informed decision. Research utilising citizens' juries in the context of screening mammography has reported promising results—Paul et al. (2008) and Baena-Cañada et al. (2018) conducted a citizen's jury with 11 and 13 women, respectively, to understand the public's opinion on changing the provision of national screening mammography services, and regarded the approach as a feasible way in which public opinion can be gathered, and used to inform policy.

As suggested in Study 4 (Chapter 6) and within this chapter, future research should be conducted to explore GPs clinical skills in facilitating shared decision-making and provide/produce relevant educational supports if such skills are lacking. As facilitating shared decision-making, in part, requires GPs to elicit and respect each patient's values and decisions, and the findings of Study 2 and Study 4 (Chapter 4 and 6) suggest that some GPs engage in paternalistic practice, I recommend the provision of professional development opportunities that promote critical reflection upon GPs own values in relation to screening mammography. As demonstrated by the work of Parker et al. (2015b, 2015c) and Parker and Carter (2016), health expert's communication of screening mammography is influenced by their prioritisation of ethical values. As such, critical reflection that aims to enhance GPs awareness of their own reasoning is an initial step towards broadening their perspectives, thus being open to the prioritisation of autonomy in practice. Further to this, self-critical reflection is recognised as an important process in being able to facilitate their patients' critical reflection (Atkins, 2006). As such, specific activities should promote critical reflection on GPs own values towards screening; highlight the socio-cultural, historical, and political processes that influence women’s willingness to screen; showcase the bias inherent in mass media that may inform women knowledge of screening; and promote shared decision-making as an important part of clinical practice. As discussed in Study 4 (Chapter 6), educational interventions that trigger cognitive dissonance between current and more appropriate ways of client care contribute to positive changes in clinical practice (i.e., more egalitarian and empathic behaviour towards patients; Sukhera et al., 2018).

In light of the findings of Study 2 (Chapter 4), wherein women were shown to negotiate subject positions with the available discourse in their socio-cultural environment, and Study 3 (Chapter 5), wherein mass media was shown to perpetuate subject positions that limit women’s opportunities for informed choice, future research should explore explicitly how women respond to media representations. As such, it would be worthwhile to create and present media representations that offer diverse breast health experiences to women and examine women’s responses. Specifically, the research would explore how diversified media representations contribute to increasing women’s experience of screening mammography as a choice. Driven by my theoretical perspective (i.e., “ways of being” are constructed and bounded by the socio-cultural, historical, and political environment; Foucault, 1972) and identification of similar subject positions across context (discourse of women, mass media and GPs), offering media representations that embody the “consider an offer” approach, should then make available subject positions that facilitate choice in the breast screening context. Further to this, it would also be pertinent, when manipulating mass media representations, that participants embody a number of varied sociodemographic variables. Research has shown correlations between sociodemographic variables and preferences for shared decision-making (Chamot et al., 2004; Levinson et al., 2005; Say et al., 2006) that may represent the wider cultural milieu. As such, it is reasonable to suggest that, women of varying demographic variables may respond differently to media representations based on cohort effects—the socio-cultural, historical, and political environment in which they grew up. Overall, by altering/improving the media representations available to women, a better understanding of how women of varying demographics draw upon media to construct and take-up subject positions in the screening mammography context is facilitated (McGannon et al., 2016).

Finally, as my thesis explored the discourses related only to the experiences of cisgender women, future research may explore what subject positions are made available within breast health discourses to other genders. A nationwide cohort study compared the incidence of breast cancer in transgender people in the Netherlands compared to the general Dutch population and identified that trans women, due to hormone treatment, had a higher incidence of breast cancer than cisgender men, and lower incidence than cisgender women, while trans men had a lower incidence of breast cancer than cisgender women and a higher incidence than cisgender men (de Blok et al., 2019). Only BreastScreen Victoria, BreastScreen New South Wales, and BreastScreen Western Australia provide guidelines related to breast health for transgender people. BreastScreen Victoria and BreastScreen New South Wales suggest that trans men who have not undergone top surgery (i.e., gender affirming chest surgery), attend screening mammography biennially between the ages of 50-74 years of age, that trans men who have undergone top surgery consult with a GP about their individual risk factors, that trans women using gender-affirming hormones for more than 5 years engage in biennial screening between the ages of 50 and 74 years, and that trans women who have been using gender-affirming hormones for less than 5 years do not screen (https://www.breastscreen.org.au/get-involved/in-your-community/trans-and-gender-diverse-people/, https://www.breastscreen.nsw.gov.au/about-screening-mammograms/information-for-trans-and-gender-diverse-people/). BreastScreen Western Australia does not make a recommendation on screening mammography for either trans men or trans women; however, recommends that trans women engage in breast awareness and should seek medical attention in response to any breast changes (https://www.breastscreen.health.wa.gov.au/Breast-health/FAQs). Given that transgender people are still at risk of developing breast cancer and that policy, in some states, supports access to the national screening mammography program, an exploration of the subject positions made available in society's discourse for transgender people, and their impact on behaviour (i.e., service access), are important avenues of future research. Research of this type would complement current efforts by government bodies (i.e., BreastScreen Victoria) in enacting transgender and gender diverse services at BreastScreen services (see Conneely et al., 2019).

7.6 Concluding Remarks

Calls to enhance informed decision-making in the breast screening context are growing (Entwistle et al., 2008; Hersch et al., 2017). In response, an array of efforts has been made to support women in making an informed decision—critical analysis of educational resources (Jørgensen & Gøtzsche, 2004, 2006), development of decision-aids (Hersch et al., 2015; Mathieu et al., 2010), and explorations of barriers to shared decision-making (Hoffman et al., 2010; Joseph-Williams et al., 2014). Although important, informed by Foucault's ideas on power/knowledge, discourse, and governmentality, and feminist-procedural accounts of autonomy, these efforts are insufficient in supporting choice within the breast screening context. I argue that they neglect the influence of socio-cultural, historical, and political processes on decision-making; and/or inherently privilege the notion of the liberal self within autonomy; and this provides a gendered conceptualisation that precludes women from autonomous decision-making (Dodds, 2000). Adopting a Foucauldian-feminist perspective allowed the present research to attune to the influence of socio-cultural processes on women's opportunity for informed decision-making in the breast screening context. Therefore, the overarching aim of this study was to explore if women were provided opportunities to make an informed decision in the breast screening context. Across the four interrelated studies, the present research has provided suggestions for a reconceptualisation of informed consent, identified how women's autonomy in informed decision-making is either discursively facilitated or undermined, and contributed to a growing body of literature that recognises how discourse acts to constitute certain ways of being.

The thesis has made a substantial contribution to identifying practices and processes that may facilitate choice within the breast screening context for cisgender women by identifying that screening mammography is rarely discursively constructed as a choice, that value-laden subject positions are constituted in screening mammography related discourse, and by highlighting specific ways in which language can be used to challenge this construction and enhance autonomy. To summarise, the present findings indicated that screening mammography is not constructed as a choice within discourse used by mass media, nor most of the discourse used by health professionals and women. Many of the associated subject positions identified moralised screening attendance, denoted women who attend as responsible, while women who do not as irresponsible, and/or inherently positioned women as attenders. However, several discourses were identified as having capacity to enhance autonomy (i.e., by legitimising a greater range of breast health behaviours and/or opening opportunities for discussion about screening mammography) when used in particular ways—Risk, Expert, Government, Professional Responsibility, Public Health, and Science. Alternatively, several discourses were identified as autonomy undermining when used in particular ways—Science, Government, Public Health, Professional Responsibility, and Paternalism, Expert, and Nationalistic.

It is hoped that the present findings will contribute to changes in policy, clinical practice, and communication that aim to enhance opportunities for choice and dissolve value-laden ways of being within the current breast screening context. I have made several clinical recommendations to policy, practice, and communication that draw on the findings of the present research, and that of other work, to enact such changes—I recommend the discursive reframing of informed consent to informed choice, the adoption of the “consider an offer” approach in policy, practice and marketing media, the use of Elwyn et al.’s (2012) three step-model to enact shared decision-making in the clinical encounter, and the adoption of autonomy enhancing discourse during the clinical encounter. By enacting the proposed recommendations, it is possible that emerging generations of women will be socialised within a world that inherently respects their bodily autonomy—equally and/or above the expertise of machines and medical professionals. As such, choice will be inherent in their decision to participate, or not participate, in the screening mammography programs.

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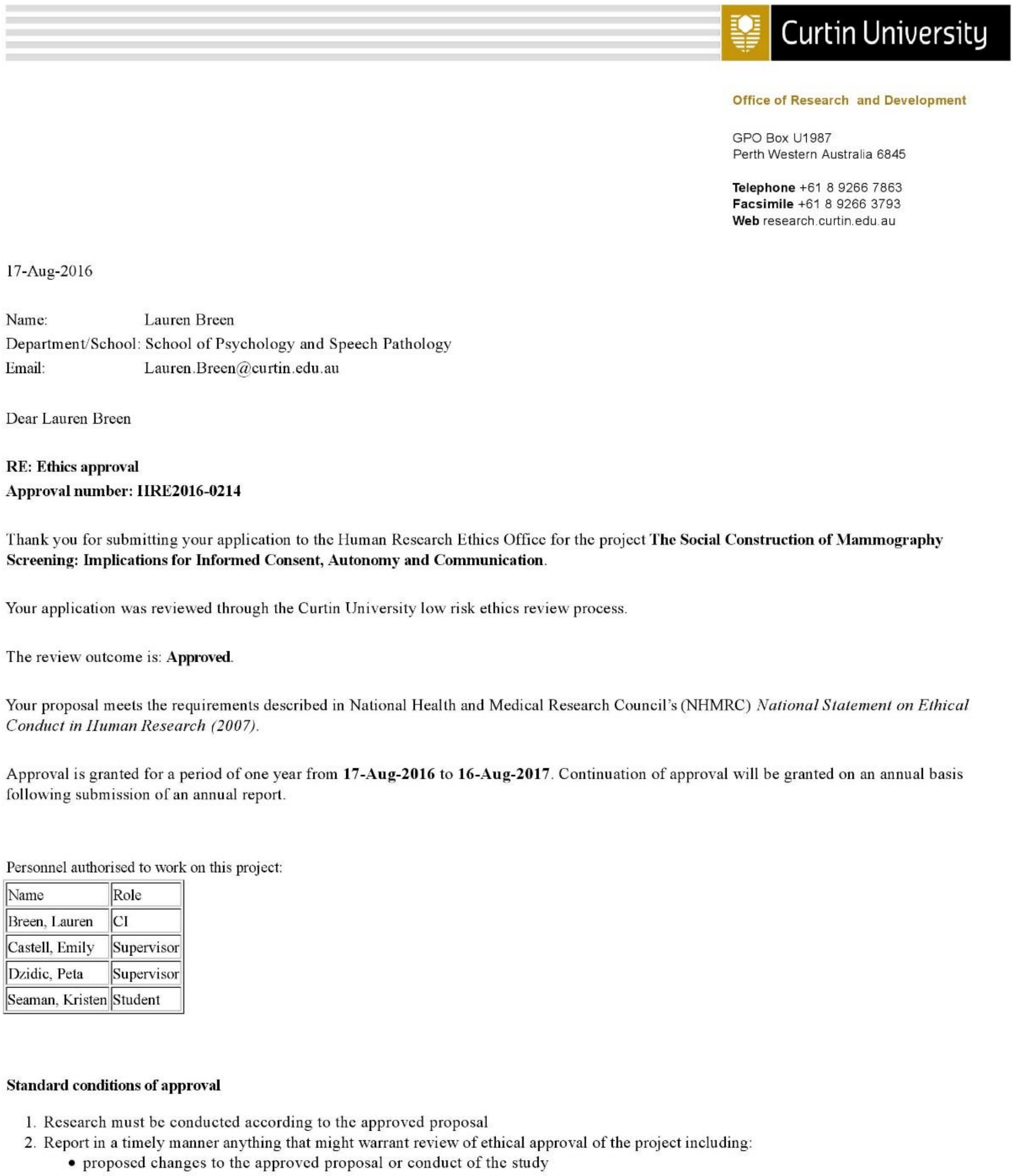

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17-Aug-2016

Name: Lauren Breen
Department/School: School of Psychology and Speech Pathology
Email: Lauren.Breen@curtin.edu.au

Dear Lauren Breen

RE: Ethics approval
Approval number: HRE2016-0214

Thank you for submitting your application to the Human Research Ethics Office for the project **The Social Construction of Mammography Screening: Implications for Informed Consent, Autonomy and Communication**.

Your application was reviewed through the Curtin University low risk ethics review process.

The review outcome is: **Approved**.

Your proposal meets the requirements described in National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007).*

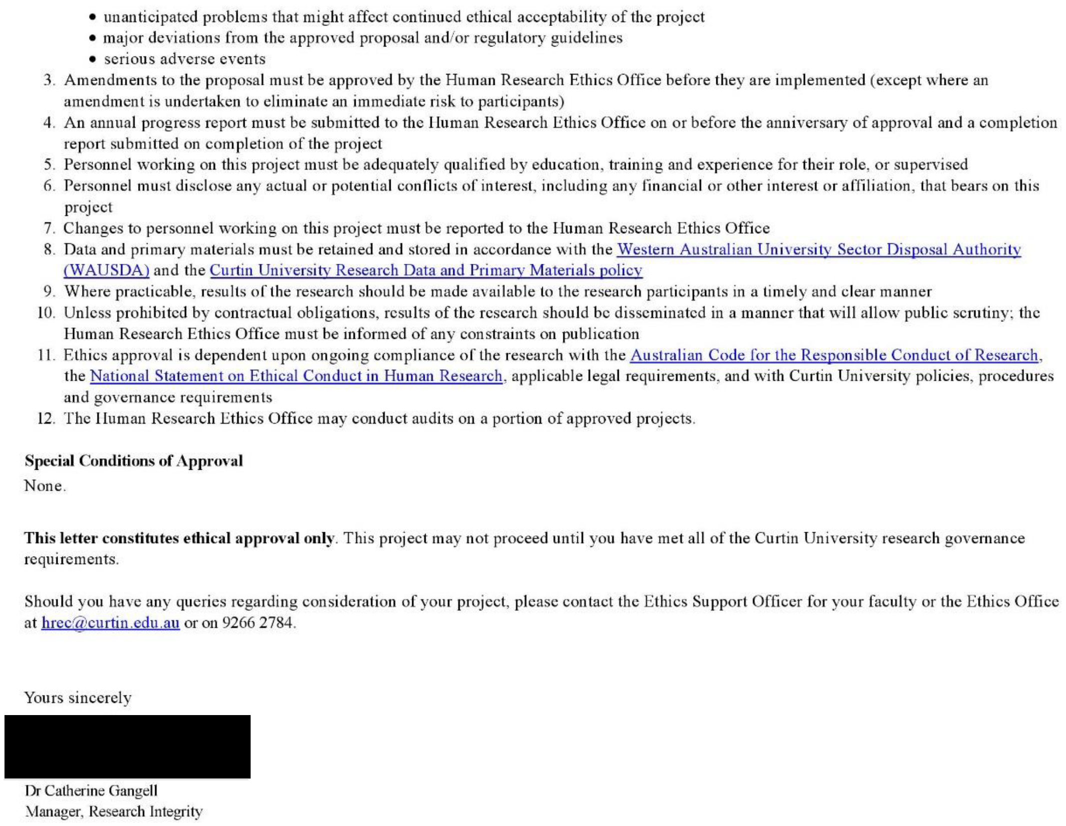
Approval is granted for a period of one year from **17-Aug-2016** to **16-Aug-2017**. Continuation of approval will be granted on an annual basis following submission of an annual report.

Personnel authorised to work on this project:

Name	Role
Breen, Lauren	CI
Castell, Emily	Supervisor
Dzidic, Peta	Supervisor
Seaman, Kristen	Student

Standard conditions of approval

1. Research must be conducted according to the approved proposal
2. Report in a timely manner anything that might warrant review of ethical approval of the project including:
    - proposed changes to the approved proposal or conduct of the study



  - unanticipated problems that might affect continued ethical acceptability of the project
  - major deviations from the approved proposal and/or regulatory guidelines
  - serious adverse events

3. Amendments to the proposal must be approved by the Human Research Ethics Office before they are implemented (except where an amendment is undertaken to eliminate an immediate risk to participants)
4. An annual progress report must be submitted to the Human Research Ethics Office on or before the anniversary of approval and a completion report submitted on completion of the project
5. Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised
6. Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
7. Changes to personnel working on this project must be reported to the Human Research Ethics Office
8. Data and primary materials must be retained and stored in accordance with the Western Australian University Sector Disposal Authority (WAUSDA) and the Curtin University Research Data and Primary Materials policy
9. Where practicable, results of the research should be made available to the research participants in a timely and clear manner
10. Unless prohibited by contractual obligations, results of the research should be disseminated in a manner that will allow public scrutiny; the Human Research Ethics Office must be informed of any constraints on publication
11. Ethics approval is dependent upon ongoing compliance of the research with the Australian Code for the Responsible Conduct of Research, the National Statement on Ethical Conduct in Human Research, applicable legal requirements, and with Curtin University policies, procedures and governance requirements
12. The Human Research Ethics Office may conduct audits on a portion of approved projects.

Special Conditions of Approval

None.

This letter constitutes ethical approval only. This project may not proceed until you have met all of the Curtin University research governance requirements.

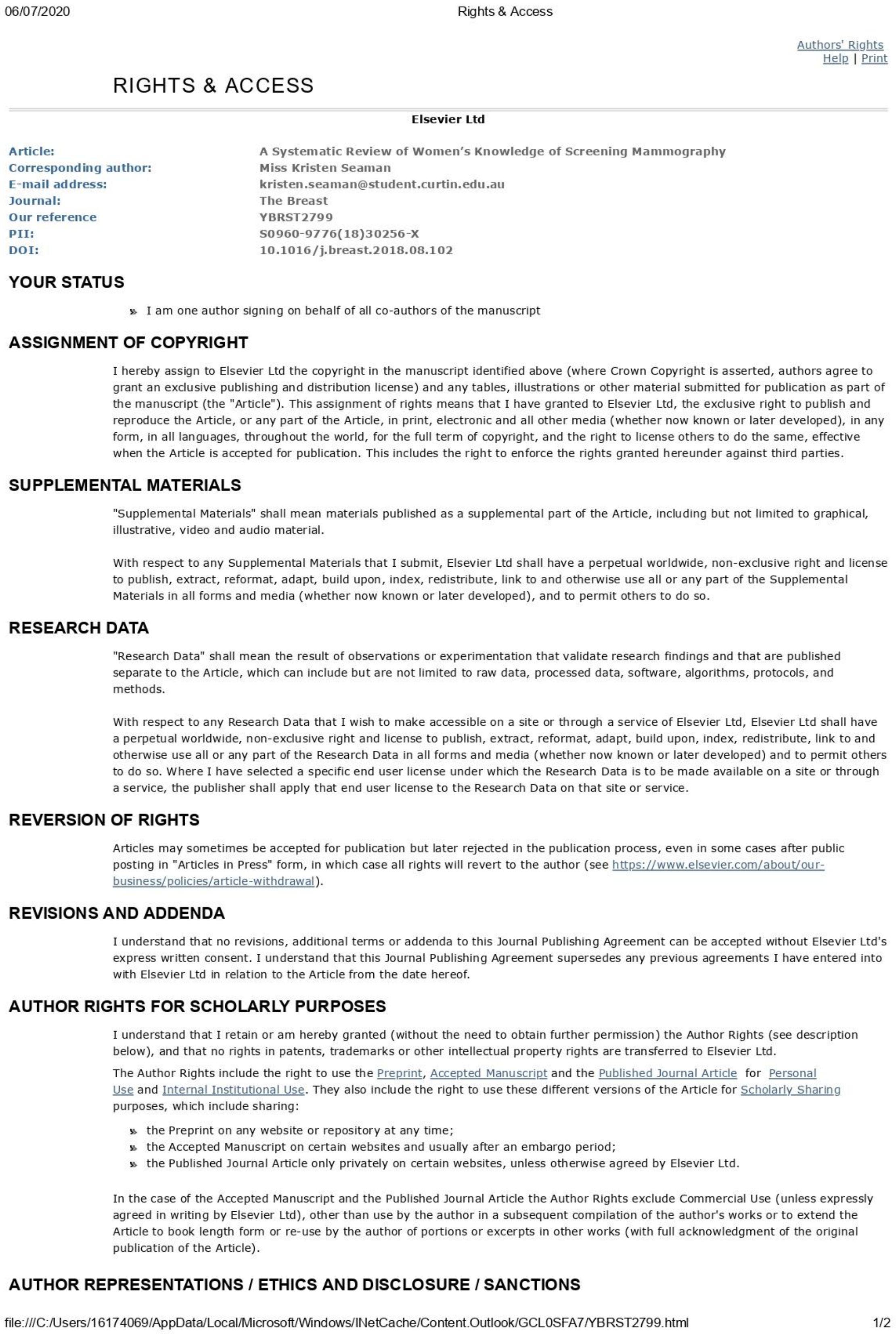
Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

[redacted]

Dr Catherine Gangell
Manager, Research Integrity

Appendix B: Study 1 Copyright Agreement



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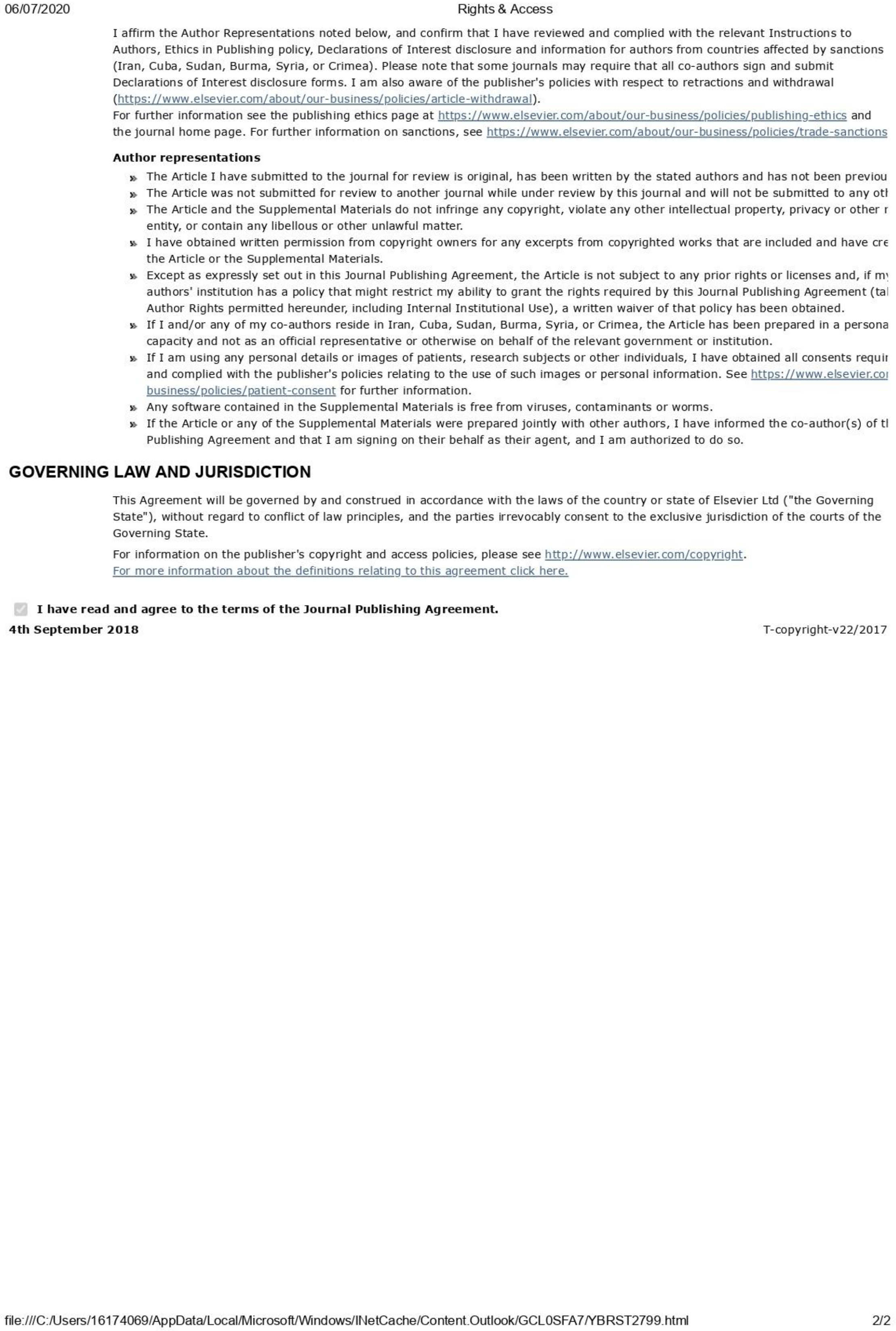

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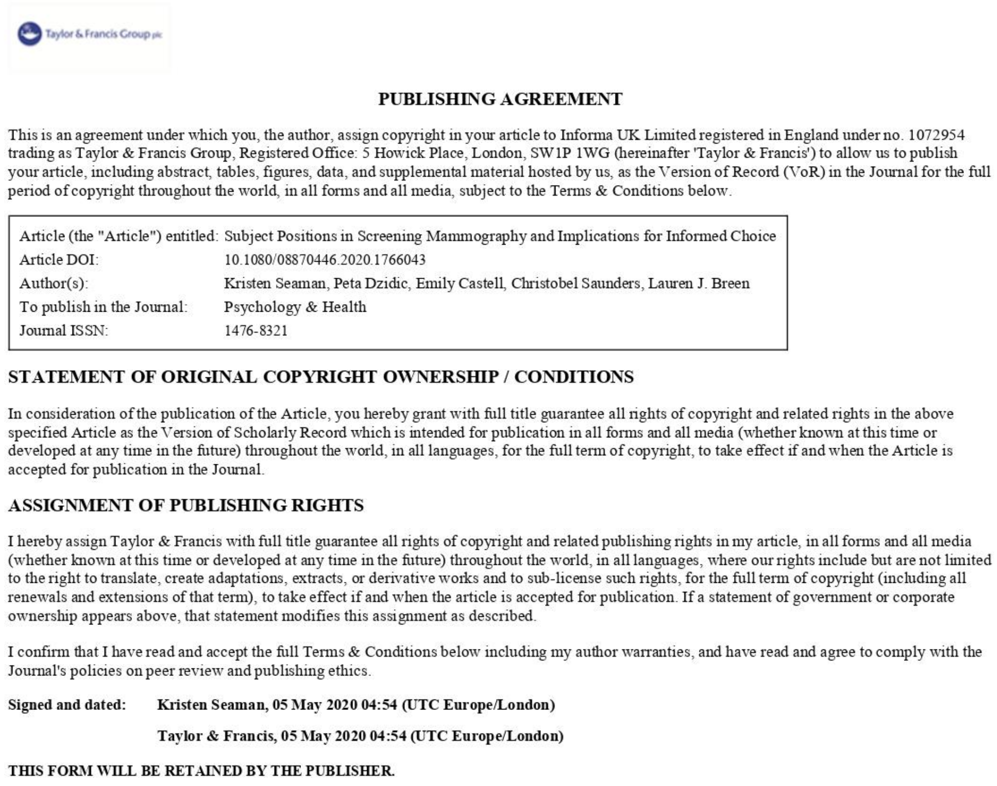

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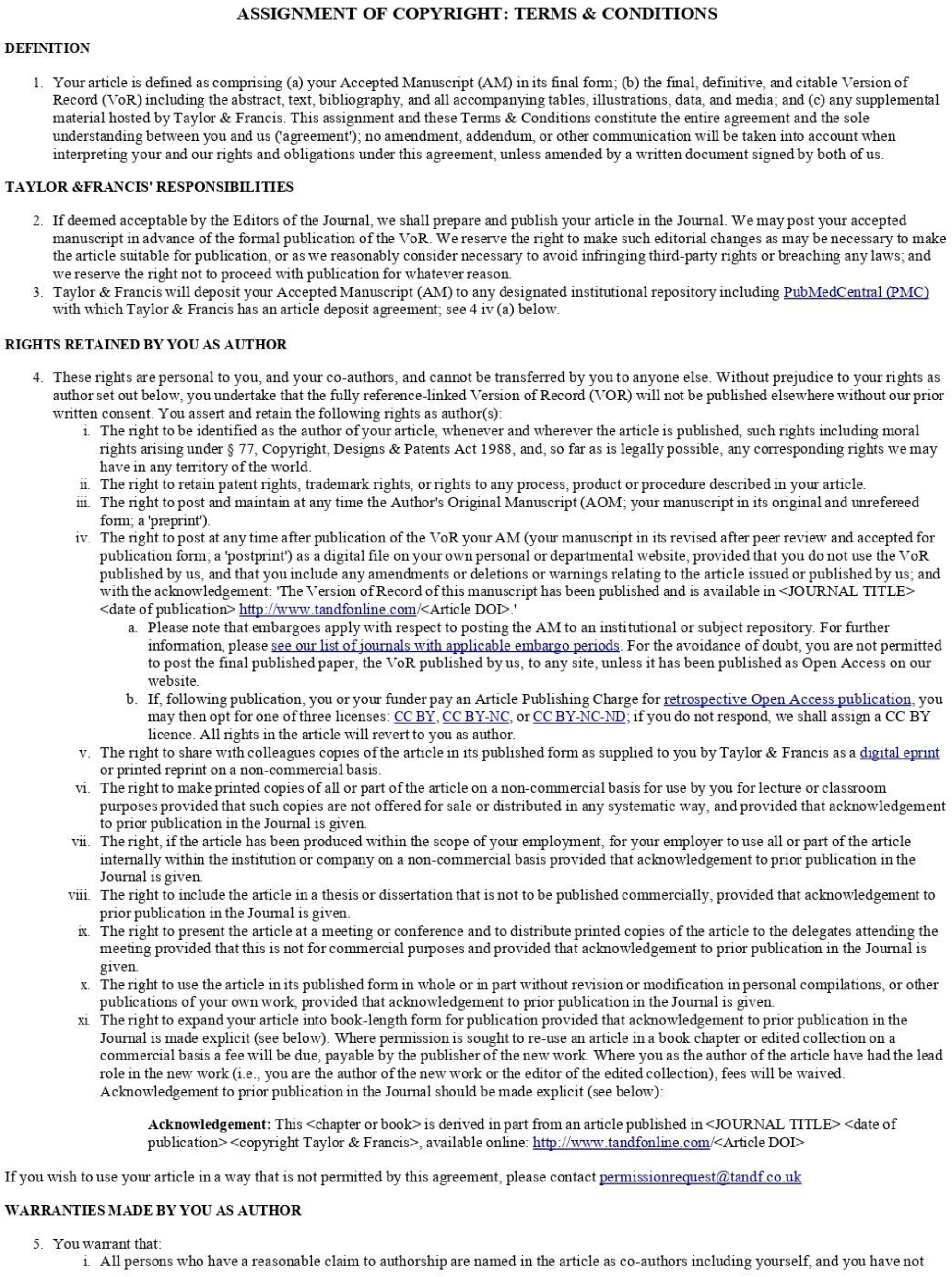

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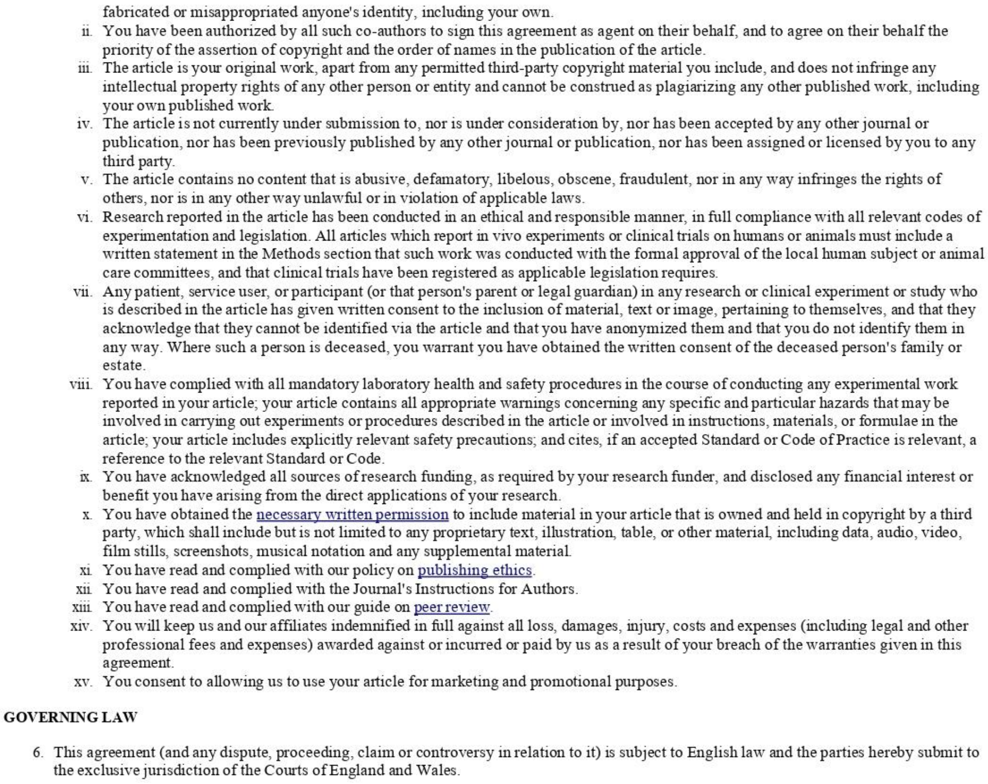

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iii. The article is your original work, apart from any permitted third-party copyright material you include, and does not infringe any intellectual property rights of any other person or entity and cannot be construed as plagiarizing any other published work, including your own published work.
iv. The article is not currently under submission to, nor is under consideration by, nor has been accepted by any other journal or publication, nor has been previously published by any other journal or publication, nor has been assigned or licensed by you to any third party.
v. The article contains no content that is abusive, defamatory, libelous, obscene, fraudulent, nor in any way infringes the rights of others, nor is in any other way unlawful or in violation of applicable laws.
vi. Research reported in the article has been conducted in an ethical and responsible manner, in full compliance with all relevant codes of experimentation and legislation. All articles which report in vivo experiments or clinical trials on humans or animals must include a written statement in the Methods section that such work was conducted with the formal approval of the local human subject or animal care committees, and that clinical trials have been registered as applicable legislation requires.
vii. Any patient, service user, or participant (or that person's parent or legal guardian) in any research or clinical experiment or study who is described in the article has given written consent to the inclusion of material, text or image, pertaining to themselves, and that they acknowledge that they cannot be identified via the article and that you have anonymized them and that you do not identify them in any way. Where such a person is deceased, you warrant you have obtained the written consent of the deceased person's family or estate.
viii. You have complied with all mandatory laboratory health and safety procedures in the course of conducting any experimental work reported in your article; your article contains all appropriate warnings concerning any specific and particular hazards that may be involved in carrying out experiments or procedures described in the article or involved in instructions, materials, or formulae in the article; your article includes explicitly relevant safety precautions; and cites, if an accepted Standard or Code of Practice is relevant, a reference to the relevant Standard or Code.
ix. You have acknowledged all sources of research funding, as required by your research funder, and disclosed any financial interest or benefit you have arising from the direct applications of your research.
x. You have obtained the necessary written permission to include material in your article that is owned and held in copyright by a third party, which shall include but is not limited to any proprietary text, illustration, table, or other material, including data, audio, video, film stills, screenshots, musical notation and any supplemental material.
xi. You have read and complied with our policy on publishing ethics.
xii. You have read and complied with the Journal's Instructions for Authors.
xiii. You have read and complied with our guide on peer review.
xiv. You will keep us and our affiliates indemnified in full against all loss, damages, injury, costs and expenses (including legal and other professional fees and expenses) awarded against or incurred or paid by us as a result of your breach of the warranties given in this agreement.
xv. You consent to allowing us to use your article for marketing and promotional purposes.

GOVERNING LAW

6. This agreement (and any dispute, proceeding, claim or controversy in relation to it) is subject to English law and the parties hereby submit to the exclusive jurisdiction of the Courts of England and Wales.

Appendix D: Systematic Review Protocol Registration

UNIVERSITY of York
Centre for Reviews and Dissemination

NHS
National Institute for
Health Research

PROSPERO International prospective register of systematic reviews

A systematic review of women's knowledge of screening mammography: protocol of a systematic review

Kristen Seaman, Lauren Breen, Emily Castell, Christobel Saunders, Peta Dzidic

Citation

Kristen Seaman, Lauren Breen, Emily Castell, Christobel Saunders, Peta Dzidic. A systematic review of women's knowledge of screening mammography: protocol of a systematic review. PROSPERO 2016:CRD42016045225 Available from http://www.crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=CRD42016045225

Review question(s)

To systematically review the literature for both qualitative and quantitative research that explores women's knowledge of screening mammography

Searches

The literature search strategy will search both key databases (PubMed, All Journals@Ovid -Abstracts and Full Text, Scopus, PsycINFO, Google Scholar and ProQuest Central) and subject specific databases (DoPHER, EPPI-Centre and The National Institute for Health care Excellence (NICE). Grey Literature will also be considered; this includes conferences papers/proceedings, reports, published abstracts, dissertations and theses. To search for dissertations and theses, ProQuest Dissertations & Theses Database (PQDT) will be used. To search for other grey literature we will use NHS Evidence and Open Grey. In addition, we will hand search key journals such as Cancer Forum and the European Journal of Cancer Prevention. Furthermore, we will examine the reference list of prominent papers and conduct citations searchers using Web of Science (science and social science citation index). To ensure thoroughness, experts in the field, including an oncologist and breast cancer specialist, will be consulted to identity any relevant papers and databases.

The review will not impose any limits on study methodologies or dates. Only studies in English or easily translated to English will be used. The data sources, cited above, will be used. Search strategies will be adapted to suit each databases, however an example of search terms to be used in PubMed are as follows;

Concept one: Women OR Female

Concept two: Knowledge OR Awareness OR Understanding OR Attitude OR Perception

Concept three: Mammogra* OR "Screening Mammography " OR "Mammograph* Screening" OR "Breast Screening Mammography" OR "Cancer Screening" OR "Breast Cancer Screening"

Prior to analysis and publication, searchers will be re-run to ensure the review has included up to date studies.

Types of study to be included Inclusion:

- Articles in English or where translation to English is available.

- Studies presenting qualitative and/or quantitative data on the topic (no restrictions on study designs will be made and interpretation of qualitative/quantitative analysis will be made together).

- The study's results/findings report on women's knowledge of screening mammography (this may include intervention studies where pre/post knowledge is collected or in response to policy changes e.g. mammography screening decision aid, both pre/post knowledge data from participants will be used or research investigating if women understand updated guidelines; current knowledge level will be taken).

- Studies for inclusion may report on men's knowledge of screening mammography however only data from women will be used.

- Study participants must be 40 years of age and older. If this is unclear, the percentage of women over 40 must be >50% or have a mean age of 50.

- Studies must present original data; duplicates/multiple publications using the same data will only be used once.

- Studies must conduct research on countries that have a National Screening Programme and are members of the International Cancer Screening Network – Breast Cancer division.

Exclusion:

- Non-English articles where no translation is available.

- No availability of full text (after exhaustive efforts to obtain have failed).

- Any parts of articles related to other methods of screening mammography (e.g. clinical and self-breast exams, genetic screening, ultrasound, and magnetic resonance imaging). The review will only include data on screening mammography.

- Any articles solely reporting on participants who have had breast cancer and/or currently have breast cancer and/or undergoing treatment. The review aims to review the 'general' population's understandings of screening mammography.

- Studies solely reporting on men's knowledge of screening mammography

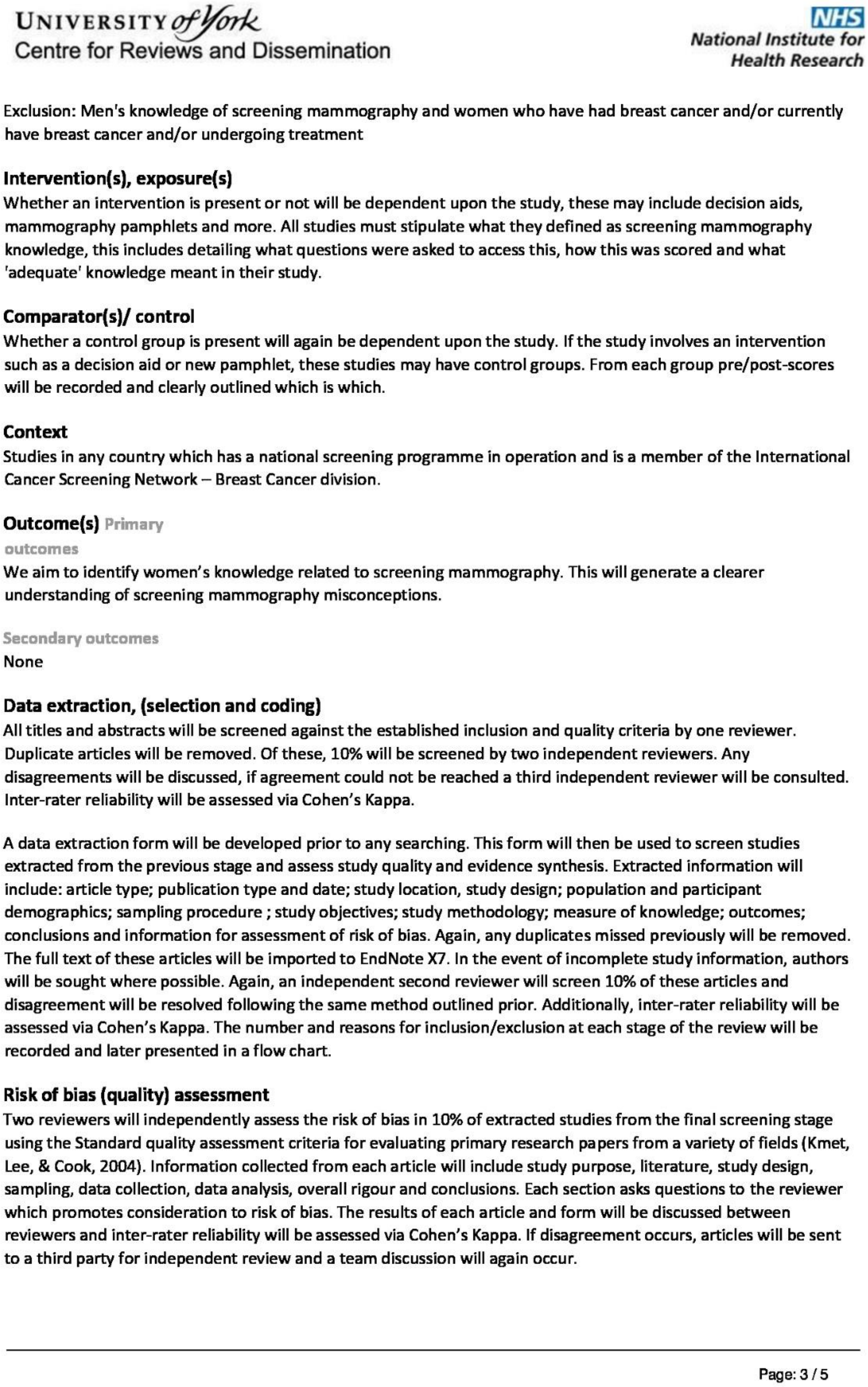
Condition or domain being studied

The literature suggests most women over-estimate the benefits of mammography screening (Chamot & Perneger, 2001; Domenighetti et al., 2003; Webster & Austoker, 2006). In one study, 45% of women believed the purpose of mammography screening was to prevent cancer (Webster & Austoker, 2006), whilst in another 68% of women stated breast screening prevents or reduces the risk of getting breast cancer (Domenighetti et al., 2003). Women also overestimated the benefit to mortality; more than half of the women in studies examining perceptions of mammography estimated mortality reduction to be 50-70% (Chamot & Perneger, 2001; Domenighetti et al., 2003). Conversely, women underestimate harm. Studies show women appear surprised when presented with overdiagnosis information and had minimal awareness of overdiagnosis (Hersch, Barratt, et al., 2014; Hersch, Jansen, et al., 2014; Waller, Douglas, Whitaker, & Wardle, 2013). Further studies reported 32% of women were not aware of false negatives (Webster & Austoker, 2006) and 8% of women were unaware mammograms have potential harming effects on healthy women (Schwartz, Woloshin, Fowler Jr, & Welch, 2004). Finally, misconceptions pertaining to age have been reported; 83% of women stated mammography had 'proven' benefit for women aged 40-49 years whilst 38% cited 'proven' benefit for women under 40 (Woloshin et al., 2000).

These prevailing misconceptions pose implications for the ethics of mammography practice, especially in terms of autonomy and informed consent. To date, no systematic review has been conducted synthesising research outlining women's current knowledge of screening mammography. In light of individual research demonstrating a high degree of erroneous beliefs, the systematic review will prove instrumental in generating a clearer understanding of prevailing screening mammography misconceptions. This will be of great value to those in the public health promotion and health policy sectors and may be useful when developing strategies to improve breast health communication and autonomous and informed decision making.

Participants/ population

Inclusion: Women aged 40 and above, of any ethnicity and living within a country which has a national breast screening programme and is a member of the International Cancer Screening Network – Breast Cancer division. Additionally, women who have not had breast cancer/currently have breast cancer



Exclusion: Men's knowledge of screening mammography and women who have had breast cancer and/or currently have breast cancer and/or undergoing treatment

Intervention(s), exposure(s)

Whether an intervention is present or not will be dependent upon the study, these may include decision aids, mammography pamphlets and more. All studies must stipulate what they defined as screening mammography knowledge, this includes detailing what questions were asked to access this, how this was scored and what 'adequate' knowledge meant in their study.

Comparator(s)/ control

Whether a control group is present will again be dependent upon the study. If the study involves an intervention such as a decision aid or new pamphlet, these studies may have control groups. From each group pre/post-scores will be recorded and clearly outlined which is which.

Context

Studies in any country which has a national screening programme in operation and is a member of the International Cancer Screening Network – Breast Cancer division.

Outcome(s)

Primary outcomes

We aim to identify women's knowledge related to screening mammography. This will generate a clearer understanding of screening mammography misconceptions.

Secondary outcomes

None

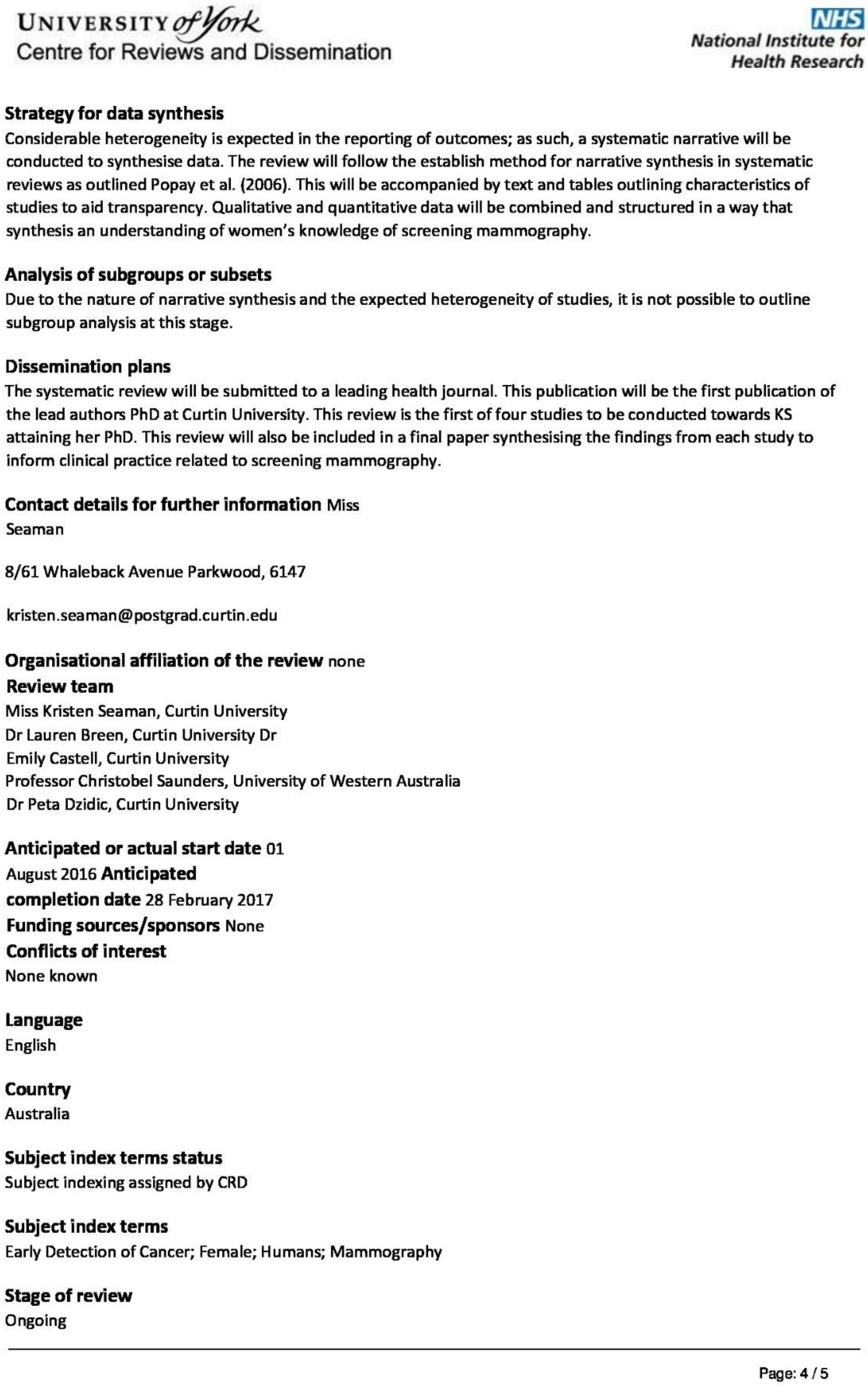
Data extraction, (selection and coding)

All titles and abstracts will be screened against the established inclusion and quality criteria by one reviewer. Duplicate articles will be removed. Of these, 10% will be screened by two independent reviewers. Any disagreements will be discussed, if agreement could not be reached a third independent reviewer will be consulted. Inter-rater reliability will be assessed via Cohen's Kappa.

A data extraction form will be developed prior to any searching. This form will then be used to screen studies extracted from the previous stage and assess study quality and evidence synthesis. Extracted information will include: article type; publication type and date; study location, study design; population and participant demographics; sampling procedure ; study objectives; study methodology; measure of knowledge; outcomes; conclusions and information for assessment of risk of bias. Again, any duplicates missed previously will be removed. The full text of these articles will be imported to EndNote X7. In the event of incomplete study information, authors will be sought where possible. Again, an independent second reviewer will screen 10% of these articles and disagreement will be resolved following the same method outlined prior. Additionally, inter-rater reliability will be assessed via Cohen's Kappa. The number and reasons for inclusion/exclusion at each stage of the review will be recorded and later presented in a flow chart.

Risk of bias (quality) assessment

Two reviewers will independently assess the risk of bias in 10% of extracted studies from the final screening stage using the Standard quality assessment criteria for evaluating primary research papers from a variety of fields (Kmet, Lee, & Cook, 2004). Information collected from each article will include study purpose, literature, study design, sampling, data collection, data analysis, overall rigour and conclusions. Each section asks questions to the reviewer which promotes consideration to risk of bias. The results of each article and form will be discussed between reviewers and inter-rater reliability will be assessed via Cohen's Kappa. If disagreement occurs, articles will be sent to a third party for independent review and a team discussion will again occur.



Strategy for data synthesis

Considerable heterogeneity is expected in the reporting of outcomes; as such, a systematic narrative will be conducted to synthesise data. The review will follow the establish method for narrative synthesis in systematic reviews as outlined Popay et al. (2006). This will be accompanied by text and tables outlining characteristics of studies to aid transparency. Qualitative and quantitative data will be combined and structured in a way that synthesis an understanding of women's knowledge of screening mammography.

Analysis of subgroups or subsets

Due to the nature of narrative synthesis and the expected heterogeneity of studies, it is not possible to outline subgroup analysis at this stage.

Dissemination plans

The systematic review will be submitted to a leading health journal. This publication will be the first publication of the lead authors PhD at Curtin University. This review is the first of four studies to be conducted towards KS attaining her PhD. This review will also be included in a final paper synthesising the findings from each study to inform clinical practice related to screening mammography.

Contact details for further information Miss Seaman

8/61 Whaleback Avenue Parkwood, 6147

kristen.seaman@postgrad.curtin.edu

Organisational affiliation of the review none

Review team

Miss Kristen Seaman, Curtin University
Dr Lauren Breen, Curtin University Dr
Emily Castell, Curtin University
Professor Christobel Saunders, University of Western Australia
Dr Peta Dzidic, Curtin University

Anticipated or actual start date 01 August 2016 **Anticipated completion date** 28 February 2017

Funding sources/sponsors None

Conflicts of interest

None known

Language

English

Country

Australia

Subject index terms status

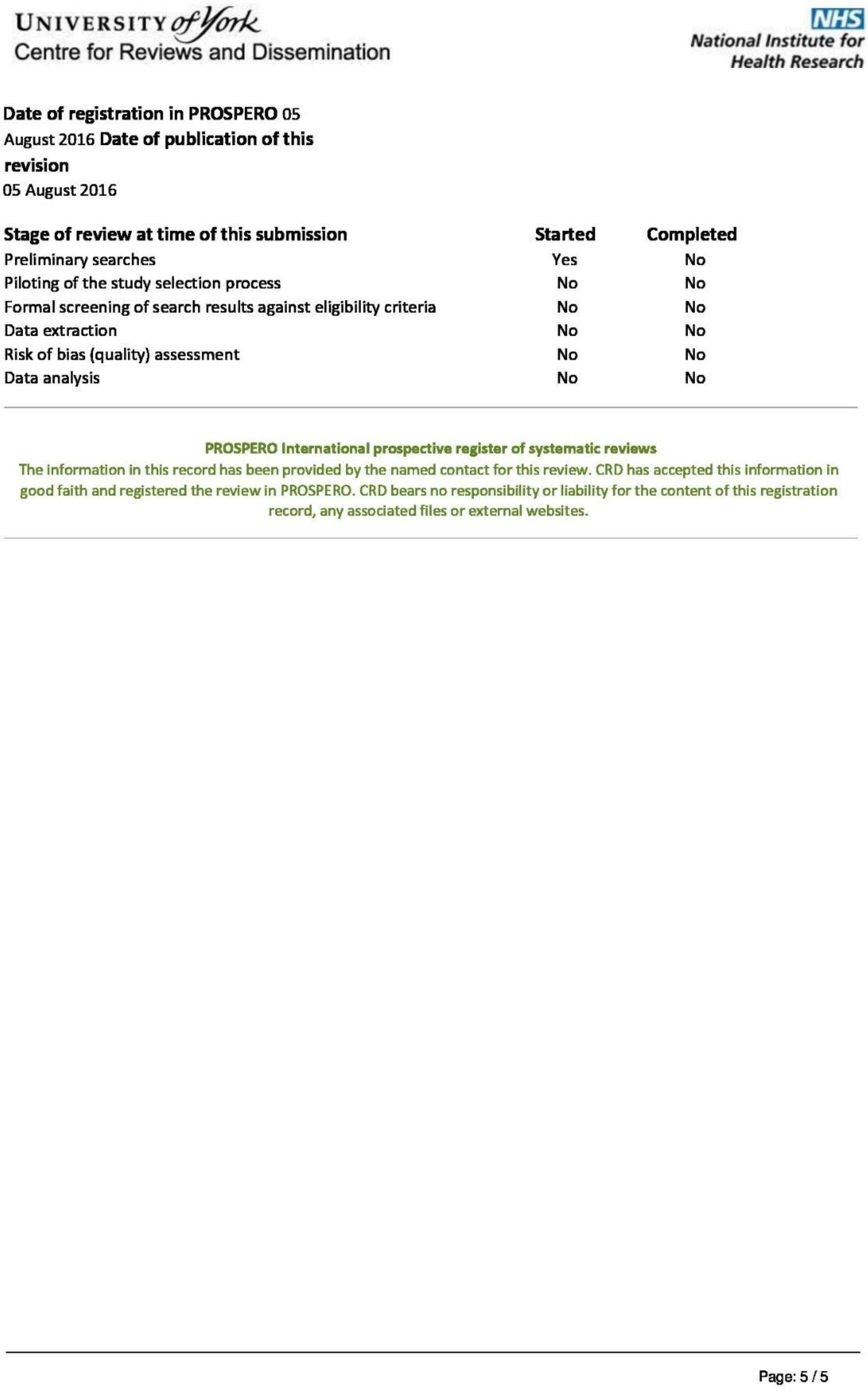
Subject indexing assigned by CRD

Subject index terms

Early Detection of Cancer; Female; Humans; Mammography

Stage of review

Ongoing



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Centre for Reviews and Dissemination

NHS
National Institute for Health Research

Date of registration in PROSPERO 05 August 2016 **Date of publication of this revision**
05 August 2016

Stage of review at time of this submission	**Started**	**Completed**
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Appendix E: Study 2 Participant Information Sheet

PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	RDHS-139-15
Project Title:	The Social Construction of Screening mammography: Implications for Informed Consent, Autonomy and Communication
Principal Investigator:	Associate Professor Lauren Breen
Student researcher:	Kristen Seaman
Version Number:	1
Version Date:	21/06/2016

What is the Project About?

There is a growing recognition women may not be making autonomous and informed decisions prior to engaging in screening mammography. To address this, decision aids providing women with more balanced information about screening mammography have been trialled and yielded positive results. However, little research has examined the social processes which may compel an individual to engage in screening mammography. The current research is interested in understanding the language (a social process) used when women discuss mammography. The study aims to interview a minimum of 12 women. The findings of this study will serve to illuminate if the languages used by women are autonomy supportive or undermining within the context of screening mammography. Findings will have implications for clinical practice and policies serving to ensure women are making informed and autonomous screening mammography decisions.

Who is doing the Research?

The project will be conducted by a Curtin University PhD student, Kristen Seaman, under the supervision of Dr Lauren Breen (principal investigator), Dr Peta Dzidic (supervisor), Dr Emily Castell (supervisor) and Dr Christobel Saunders (associate supervisor).

The results of this research project will be used by Kristen Seaman to obtain a Doctor of Philosophy at Curtin University and is funded by the University.

Why am I being asked to take part and what will I have to do?

You have been invited to participate in this study because you are an English-speaking women aged 40 and above with no personal history of breast cancer. If you choose to participate, you will be asked to engage in a one on one, face to face interview. This interview will take approximately 45 minutes to one hour and with your permission, be audio recorded. During the interview you will be asked about, if any, your own experiences with screening mammography, your thoughts regarding BreastScreen Australia and other’s involvement with Screening mammography. Prior to the interview, you will be asked a number of questions regarding your eligibility to participate. These will include age, gender and history of breast cancer. This can be completed over telephone or email. If you are eligible to participate in the study, a mutually convenient location and time will be arranged for the interview. Proposed interview locations include cafes, public libraries and University facilities. On arrival to the interview location you will then be provided with an information sheet, consent form and brief demographic questionnaire. You will be asked to read all forms, and if you agree, return the signed consent and demographic questionnaire. I will ask if you have any questions prior to beginning. With permission, the audio-recording will be turned on and you will be asked to provide verbal consent for your participation. If at any time you feel uncomfortable, you may terminate the audio-recording and your participation without reason or consequence. Once the interview is completed, a casual discussion will take place where you are able to express how you felt about the interview. You will also be provided with an opportunity to ask further questions. Additionally, you will be offered a recruitment poster to give to other suitable participants. You are under no obligation to hand this out. At the end of the study, I will email/post my interpretation of the collated data. This is to ensure the voices of participants are accurately captured. You will be presented with a collection of my interpretations of the collated data and provided an opportunity to change, add or remove information. You are under no obligation to engage in this process. If you wish, a final copy of the report can be sent to you when the research is completed.

Are there any benefits to being in the research project?

Whilst there are no direct benefits to you from participating in this study, the results of this research will have implications for clinical practice and policies serving to ensure women are making informed and autonomous screening mammography decisions.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

Apart from giving up your time, we do not expect that there will be any risks or inconveniences associated with taking part in this study. There will be no financial cost to you for taking part in this research and you will not be paid for participating. However, if the interview takes place at Curtin University, your parking costs will be covered for the duration of the interview.

Who will have access to my information?

The information collected in this research will be identifiable as it involves face to face interviews. Your identity will be known to myself, Kristen Seaman, as I will be conducting the interviews. After the interview, data will be de-identifiable. A professional transcription service may be used to transcribe your audio-recording. This service will have access to any identifiable information you state during the recorded section of the interview. Upon request, a copy of the chosen services privacy policy can be provided. All information will be stored securely at Curtin University. The following people will have access to the information we collect in this research: the research team and the Curtin University Ethics Committee

Hard copies of participant consent forms, and demographic survey data will be stored in a locked filing cabinet in the lockable office of the Dr Lauren Breen (principal investigator) at Curtin University's Bentley campus. At no time during the project will participant consent forms and responses from the demographic survey be linked or stored within the same file. The interview transcripts and scanned copies of the consent form and demographic survey will be saved on the Curtin University server and will only be accessible to Dr Lauren Breen and Kristen Seaman via password access. The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended and then it will be destroyed. Upon the completion of the study, research findings may be presented at conferences, to the Cancer Council, published in professional journals and media outlets. You will not be identified in any results that are published or presented.

Do I have to take part in the research project?

Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. You do not have to give us a reason; just tell us that you want to stop. Please let us know you want to stop so we can make sure you are aware of any thing that needs to be done so you can withdraw safely. If you choose to leave the study we will use any information collected unless you tell us not to.

If you decide to take part in this research we will ask you to sign the consent form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your health information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Who can I contact about the research?

If you have any questions about the study or your role, please contact Kristen Seaman via email on: kristen.seaman@postgrad.curtin.edu.au. Alternatively you can contact Dr Lauren Breen via email: Lauren.Breen@curtin.edu.au or Curtin University's School of Psychology and Speech Pathology: (08) 9266 7279.

If you have any questions of an ethical nature concerning this study, please contact the Human Research Ethics Committee. Contact information is shown directly below.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number RDHS-139-15). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

Who can I contact for more information and support about breast health?

If you have further questions regarding breast cancer detection or would like to know more, please contact one of the following organisations. Additionally, contact details of a free counselling service are provided for further support.

Cancer Australia

Website: http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer

Telephone: 1800 624 973

Breast Cancer Network Australia

Website: https://www.bcna.org.au/

Telephone: 1800 500 258

Cancer Council Australia

Website: http://www.cancer.org.au/about-cancer/types-of-cancer/breast-cancer.html

Telephone: 13 11 20

Relationships Australia

Website: www.wa.relationships.com.au

Telephone: 1300 364 277

Appendix F: Study 2 and 4 Consent Form

Curtin University

CONSENT FORM

HREC Project Number: RDHS-139-15

Project Title: The Social Construction of Screening mammography: Implications for Informed Consent, Autonomy and Communication

Principal Investigator: Associate Professor Lauren Breen

Student researcher: Kristen Seaman

Version Number: 1

Version Date: 21/06/2016

- I have read the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I consent to being audio-recorded.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).

- I understand I will receive a copy of this Information Statement and Consent Form.

Participant Name	
Participant Signature	
Date	

<u>Declaration by researcher:</u> I have supplied an Information Letter and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

Researcher Name	Kristen Seaman
Researcher Signature	
Date	

Appendix G: Study 2 Demographic Questionnaire

Please answer each question within the line/space provided.

1. What is your birth date? ____
2. Where were you born? ____
3. Country of longest residence?
4. Has anyone close to you been diagnosed with breast cancer? (E.g. family, friends, colleagues, neighbours, acquaintances etc.)
5. What is your highest level of education?
6. Have you ever worked in the healthcare sector? If yes, please describe your role.
7. Please describe your current living arrangement, or, tick from the options provided.

☐ Single
☐ Married
☐ Living with children
☐ Living with grandchildren
☐ Divorced
☐ De-facto

Appendix H: Study 2 Interview Guide

Rapport building

- Could you tell me what motivated you to participate in this research?

Understanding participants' breast cancer and screening knowledge

- Could you tell me what you know about breast cancer?
- Could you tell me any ways you know of that breast cancer can be detected?
- What do you know about mammograms?

Perceptions of own practice and self

- Could you tell me about your own experiences with any breast cancer detection methods?
- **Experiences**
  - Why do you engage in these?
    - When did you first engaging in these, why?
  - How do you feel before/during/after?
  - How would you feel if you did not engage?
    - Why would you feel this way
  - How do you think other people perceive your participation?
    - Why do you think that?
- **No Experiences**
  - Why do you choose to not engage in breast cancer detection methods?
    - How do you think other people perceive your non-participation?
      - Why do you think that?

Perceptions of others practices

- What screening practices, if any, do those around you engage in?
- Why do you think they have made this choice?
- How do you perceive women who do not engage in breast screening practices?
    - Why do you think you hold this perception?
- How do you perceive women who engage in mammograms?
    - Why do you think you hold this perception?

Perceptions of BreastScreen Australia (BSA)

- Could you tell me what you know about BSA?
- What is your opinion on the service they provide?
- What messages related to mammography do you think they promote?
    - Why do you think that?
    - Could you give me any examples?
    - Have these messages influenced your behaviour in any why?
        - Why or why not?

Sources of breast screening information

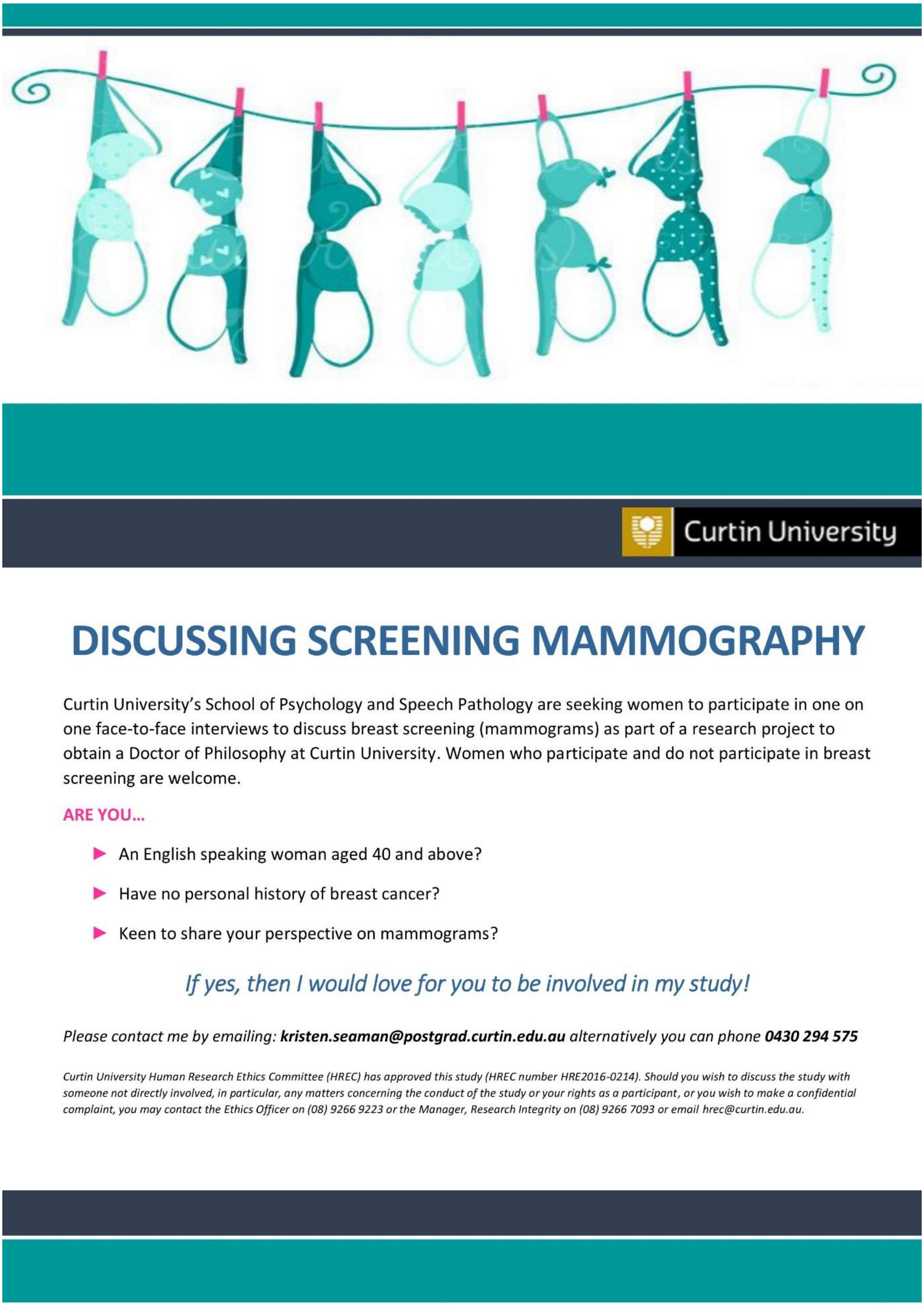
- Generally, where do you go for information about your health?
    - What about breast related-health?
    - What have your experiences been like when accessing breast related health information?
        - What were the main messages?
- What do you consider as trusted sources of information?

    - Could you give me any examples of trusted sources related to breast information?
    - Why do you consider these sources trusted?
    - Have these sources had any impact on your behaviour in relation to breast health?
- Where else have you seen breast related information advertised?
    - Could you explain to me what you think their main messages are?
    - Have they influenced your behaviour in any way?
        - Why or why not?

<u>Perceptions of informed consent</u>

- What does informed consent mean to you?
- Thinking about breast screening, what does providing informed consent mean to you?
- What are your thoughts on shared decision making?
    - How involved do you wish to be in decision making about your own breast screens? Why?
    - Have your experiences reflected this desire?
    - What information do you think should be provided to help women engaging in shared decision making?

Appendix I: Study 2 Recruitment Flyer



Curtin University

DISCUSSING SCREENING MAMMOGRAPHY

Curtin University's School of Psychology and Speech Pathology are seeking women to participate in one on one face-to-face interviews to discuss breast screening (mammograms) as part of a research project to obtain a Doctor of Philosophy at Curtin University. Women who participate and do not participate in breast screening are welcome.

ARE YOU…

- An English speaking woman aged 40 and above?
- Have no personal history of breast cancer?
- Keen to share your perspective on mammograms?

If yes, then I would love for you to be involved in my study!

Please contact me by emailing: ***kristen.seaman@postgrad.curtin.edu.au*** *alternatively you can phone* ***0430 294 575***

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2016-0214). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

Appendix J: Study 4 Participant Information Sheet

PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	RDHS-139-15
Project Title:	The Social Construction of Screening mammography: Implications for Informed Consent, Autonomy and Communication
Principal Investigator:	Associate Professor, Lauren Breen
Student researcher:	Kristen Seaman
Version Number:	1
Version Date:	21/06/2016

What is the Project About?

There is a growing recognition women may not be making autonomous and informed decisions prior to engaging in screening mammography. To address this, decision aids providing women with more balanced information about screening mammography have been trialled and yielded positive results. However, little research has examined the social processes which may compel an individual to engage in screening mammography. The current research is interested in understanding the language (a social process) used when health professionals discuss mammography with patients. The study aims to interview a minimum of 12 health professionals. The findings of this study will serve to illuminate how language used by health professionals can support women in making autonomous and informed decisions, and to better understand the practicalities faced by GPs is supporting the process. Findings will have implications for clinical practice and policies serving to ensure women are making informed and autonomous screening mammography decisions.

Who is doing the Research?

The project will be conducted by a Curtin University PhD student, Kristen Seaman, under the supervision of Associate Professor Lauren Breen (principal investigator), Dr Peta Dzidic (supervisor), Dr Emily Castell (supervisor). The results of this research project will be used by Kristen Seaman to obtain a Doctor of Philosophy at Curtin University and is funded by the University.

Why am I being asked to take part and what will I have to do?

You have been invited to participate in this study because you occupy a health professional role identified as important in the communication of screening mammography by participants in a previous study. If you choose to participate, you will be asked to engage in a one on one, face to face interview, telephone or skype interview. The interview may last up to 30 minutes. With your permission the interview will be audio recorded. During the interview you will be asked about the dialogue used when discussing mammography with women, your thoughts regarding BreastScreen Australia and women’s involvement or non-involvement with screening mammography. Prior to the interview, you will be asked your health professional role to determine eligibility. This can be completed over telephone or email. If you are eligible to participate in the study, a mutually convenient location and time will be arranged for the interview. Proposed interview locations include cafes, public libraries, workplaces and University facilities. On arrival to the interview location you will then be provided with an information sheet, consent form, $120 Myer gift card, receipt form and brief demographic questionnaire. You will be asked to read all forms, and if you agree, return the consent, demographic and receipt form signed. I will ask if you have any questions prior to beginning. With permission, the audio-recording will be turned on and you will be asked to provide verbal consent for your participation. If at any time you feel uncomfortable, you may terminate the audio-recording and your participation without reason or consequence. Once the interview is completed, a casual discussion will take place where you are able to express how you felt about the interview. You will also be provided with an opportunity to ask further questions. Additionally, you will be offered a recruitment poster to give to other suitable participants. You are under no obligation to hand this out. At the end of the study, I will email/post my interpretation of the collated data. This is to ensure the voices of participants are accurately captured. You will be presented with a collection of my interpretations of the collated data and provided an opportunity to change, add or remove information. You are under no obligation to engage in this process. If you wish, a final copy of the report can be sent to you when the research is completed.

Are there any benefits to being in the research project?

As remunerations for your time you will receive a $120 Myer gift card. Additionally, the results of this research will have implications for clinical practice and policies serving to ensure women are making informed and autonomous screening mammography decisions.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

Apart from giving up your time, we do not expect that there will be any risks or inconveniences associated with taking part in this study. There will be no financial cost to you for taking part in this research and you will not be paid for participating. However, if the interview takes place at Curtin University, your parking costs will be covered for the duration of the interview.

Who will have access to my information?

The information collected in this research will be identifiable as it involves face to face interviews. Your identity will be known to myself, Kristen Seaman, as I will be conducting the interviews. After the interview, data will be de-identifiable. A professional transcription service may be used to transcribe your audio-recording. This service will have access to any identifiable information you state during the recorded section of the interview. Upon request, a copy of the chosen services privacy policy can be provided. All information will be stored securely at Curtin University. The following people will have access to the information we collect in this research: the research team and the Curtin University Ethics Committee

Hard copies of participant consent forms, and demographic survey data will be stored in a locked filing cabinet in the lockable office of the Associate Professor Lauren Breen (principal investigator) at Curtin University's Bentley campus. At no time during the project will participant consent forms and responses from the demographic survey be linked or stored within the same file. The interview transcripts and scanned copies of the consent form and demographic survey will be saved on the Curtin University server and will only be accessible to Associate Professor Lauren Breen and Kristen Seaman via password access. The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended and then it will be destroyed. Upon the completion of the study, research findings may be presented at conferences, to the Cancer Council, published in professional journals and media outlets. You will not be identified in any results that are published or presented.

Do I have to take part in the research project?

Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. You do not have to give us a reason; just tell us that you want to stop. Please let us know you want to stop so we can make sure you are aware of any thing that needs to be done so you can withdraw safely. If you choose to leave the study we will use any information collected unless you tell us not to.

If you decide to take part in this research we will ask you to sign the consent form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your health information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Who can I contact about the research?

If you have any questions about the study or your role, please contact Kristen Seaman via email on: kristen.seaman@postgrad.curtin.edu.au. Alternatively you can contact Associate Professor Lauren Breen via email: Lauren.Breen@curtin.edu.au or Curtin University's School of Psychology and Speech Pathology: (08) 9266 7279.

If you have any questions of an ethical nature concerning this study, please contact the Human Research Ethics Committee. Contact information is shown directly below.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number RDHS-139-15). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

Who can I contact for more information and support about breast health?

If you have further questions regarding breast cancer detection or would like to know more, please contact one of the following organisations. Additionally, contact details of a free counselling service are provided for further support.

Cancer Australia

Website: http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer

Telephone: 1800 624 973

Breast Cancer Network Australia

Website: https://www.bcna.org.au/

Telephone: 1800 500 258

Cancer Council Australia

Website: http://www.cancer.org.au/about-cancer/types-of-cancer/breast-cancer.html

Telephone: 13 11 20

Relationships Australia

Website: www.wa.relationships.com.au

Telephone: 1300 364 277

Appendix K: Study 4 Demographic Questionnaire

Please answer each question within the line/space provided.

1. What is your birth date? ____
2. Where were you born? ____
3. Country of longest residence?

   ____

4. What are your professional qualifications?

   ____

   ____

5. In years, how long have you been a registered general practitioner for? __________
6. Have you had any other roles within the health sector that were not as a general practitioner? If so, what were they?

   ____

   ____

7. Do you have any specific health interests? If so, please describe

   ____

   ____

8. How did you hear about this study? ____

Appendix L: Study 4 Interview Guide

Knowledge of breast cancer and screening

- Could you tell me what you know about breast cancer?
- Could you tell me about ways to **reduce the risk of dying** from breast cancer?
    - Which of these do you recommended to women?
        - Why do you recommend this practice?
            - If mammograms have not been mentioned; mention now.

Perceptions of BreastScreen Australia (BSA)

- Could you tell me about your involvement, if any, with BSA?
- What is your opinion on the service they provide?
- What messages related to mammography do you think they promote?
    - How do these messages influence your interaction with women?

Dialogue used when discussing breast health/mammography with women

- Could you give me an example of the conversation you would have with a woman at the age of 50 about the **topic of breast health**?
- Could you give me an example of the type of conversation you would have with a woman over 74 about the **topic of breast health**?
- How would you respond to women between 50 and 74 who are not participating in the screening program?

Perceptions of participants and non-participants

- What are your thoughts about women who do not attend screening?
    - Why do you think women choose not to engage?

- What are your thoughts about women who do attend screening?
    - Why do you think they are attending the screening program?

Informed consent and shared decision making

- What does informed consent mean to you?
    - What would this look like in the breast screening context?
- What does shared decision-making in the breast screening context look like to you?
    - What do you believe are barriers to informed consent/SDM?
    - What do you believe facilitates informed consent/SDM?

Sources of breast screening information

- Where do you get your information about breast health and screening from?
- What sources of information do you provide women?
    - E.g. brochures, links to websites, posters

Summary Questions

- Is there anything you would like to add?

Appendix M: Study 4 Recruitment Flyer

Curtin University

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2016-0214

Discussing Screening Mammography

Curtin University's School of Psychology is seeking General Practitioners to participate in a 30 minute, one-on one, face-to-face, telephone or Skype interview, to understand how GPs discuss breast screening with patients. Participants will receive a voucher as a thank you for their time.

If you are interested, contact

✉ kristen.seaman@student.curtin.edu.au