

# THE CHALLENGE OF PINK: SUBVERTING THE CURRENT BREAST CANCER AWARENESS PARADIGM THROUGH VISUAL AND ORAL STORYTELLING

A Thesis submitted by

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#### Abstract

The Challenge of Pink: Subverting the Current Breast Cancer Awareness Paradigm Through Visual and Oral Storytelling is a practice-led research project that explores the living experiences of male breast cancer patients and articulates the emotional consequences of their treatment in the form of mixed-media installations. The project aims to raise awareness of male breast cancer, as males represent one in 125 diagnoses of breast cancer per year (Cancer Australia, 2021), but are largely underrepresented or not represented at all in informational literature about breast cancer in Australia and beyond. In recognising the gender disparity of representation in breast cancer awareness campaigns and literature, the artworks generated for installation aims to redress the representational imbalance by providing an alternative public awareness paradigm that gives visibility and voice to male breast cancer patients.

Using Autoethnographical representations by male breast cancer patients and applied Grounded Theory coding practices (Charmaz, 2008); this research analyses how visual and oral storytelling may subvert the gender stereotypical assumption that breast cancer is a "women's disease". The project is informed by contemporary artists including Janine Antoni (America), Haya Cohen (Australia), Dan Elborne (Australia), Ann Hamilton (America), David Jay (America), and Hanna Wilke (America) and comprises creative work (70% weighting) and an exegesis (30% weighting). The project's creative development of video, watercolour painting, textile installations, printing plates, illumination drawings, artist journals and a coding journal are demonstrative outcomes of my analysis of two interviews and 165 written stories of international male breast cancer survivors. The exhibition of these multi-modal artworks creates an inclusive representation of all breast cancer patients. This project is intended, first and foremost, to create a platform where all gender of patients' issues are heard equally, coherently and in harmony. A further project aim is to create a body of artwork that speaks to a wider audience including medical practitioners, patients and their families, and breast cancer awareness advocates, of the need for more inclusive narratives of breast cancer awareness.

## **Certification of Thesis**

This exeges is entirely the work of Alyson Baker except where otherwise acknowledged. The work is original and has not previously been submitted for any other award, except where acknowledged.

Principal Supervisor: Associate Professor Beata Batorowicz Associate Supervisor: Professor Janet McDonald

Student and supervisor's signatures of endorsement are held at the University.

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## Cultural sensitivity warning

Aboriginal and Torres Strait Islander viewers, listeners and readers are advised that the following exegesis and exhibition may contain images, names and voices of people who have died.

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# List of abbreviations

- BCNA Breast Cancer Network Australia
- MBCC Male Breast Cancer Coalition
- NBCF National Breast Cancer Foundation

# **CHAPTER ONE: INTRODUCTION**

#### 1.1. Defining the study

Drawing upon the visual arts and medical fields, this practice-led research engages in multimodal forms of storytelling to create an awareness of male breast cancer. My works incorporate multimedia, textile installations and performance among other artforms to allow for a multi-sensory storytelling experience that investigates males with breast cancer and how the current use of public awareness Honours work where I addressed my own personal diagnosis and others with breast cancer. In going through this experience, I encountered a gap in awareness for males with the disease, and how this limitation leads to broader media and societal misrepresentation(s) within a national context and beyond (J Boyages 2021, pers. comm., 1 March; King, 2004). Although some men refer to their cancer as "chest cancer" or "pec cancer" (Coding Journal 2020-2021, p. 50; Male Breast Cancer Coalition (MBCC, 2021), the body part where tumours may develop is known biologically as the "breast" and as such this research terms the disease "breast cancer" (Cancer Australia 2021). Cancer Australia (2021) has identified that males with breast cancer have a lower survival that their female counterparts, as does the National Cancer Database in America (<https://www.breastcancer.org>). Eliza Whiteside (2017, pers. comm., 17 November), a breast cancer researcher at the University of Southern Queensland, explained during my meeting with her that this is due to lack of public awareness due to 43,000 medical references to male breast cancer.

In response, my artwork aims to provide an alternative public awareness paradigm that gives visibility and voice to male breast cancer patients and a representation of a more inclusive breast cancer narrative of both female and male genders. Within this focus, I also acknowledge transgender and intersex persons and the further challenges that they face within the breast cancer context (de Blok, et al. 2019). The use of diverse materials and performative artworks reflect the tactility and embodiment of the disease, and has a physical manifestation on the bodies of breast cancer patients. By exhibiting a diversity of bodies with breast cancer, this is a strategic application that allows the viewer of the artworks to renegotiate their own understanding and perceptions of the disease. By interweaving visual art and the medical perspectives within this research project, I assert that male bodies with breast cancer are transgressive (Richardson 2016) in the current paradigm of awareness and as such they are subject to *othering* (McQuarrie, 2009) and self-abjection (McCabe 2010), leading to trauma for some patients (Leys 2000). As Eileen Thomas (2010, p, 37) nursing researcher in male breast cancer, explains: 43% of men in her study said that a breast cancer diagnosis would contest their sense of masculinity. In order to explore how to create an awareness of male breast cancer, my research challenges the female-oriented public breast cancer awareness in Australia and beyond, that might marginalise male patients so that I may offer strategies, through my arts practice, on how it may be changed and improved. In light of the overall scope of the project, this practice-led research project comprises an exegesis with a 30% weighting and 70% weighting for creative outcomes.

#### 1.2. Researcher position: My breast cancer story

This is practice-led research draws on my own experience of breast cancer, which has informed my artistic practice as well as interwoven my perspectives on art, health and wellbeing issues. Living on the Gold Coast, Australia, I was diagnosed with breast cancer on 6 February 2008. My surgical treatment began with a mastectomy on 29 February 2008 and reconstruction was completed in October 2008. I continued endocrine treatment for a further five years until late 2013. I spent most of my undergraduate years from 2009 to 2013 exploring my own experience of breast cancer and articulated my feelings in the artwork; it was a cathartic and experiential process as I began knitting breasts in a variety of yarn and sizes. I experimented in different artistic modalities to visually represent my own experience and shared my creative outcomes through several exhibitions.

During my Honours year at Griffith University (2015-2016), I explored stories of other people with breast cancer. I contacted other survivors in Australia and listened to their experiences. My arts practice evolved from articulating my own story to that of a contemporary artist-researcher who collects, analyses, collates, and curates wider stories of breast cancer. I specifically targeted people who sat outside the Australian breast cancer screening criteria – as Queensland Health explains, women between the ages of 40 and 75 are eligible for a free breast screen (<www.goldcoast.health.gov.au>). It was during my Honours research that I found that males' survival rate was proportionally lower than for women. Male patients also appeared invisible in the visual images and stories about breast cancer (Breast Cancer Network Australia (BCNA, 2021). This supported my initial 'hunch' that men were being marginalised in the current paradigm of awareness due to the overwhelming national branding of breast cancer as feminine (BCNA 2016, p. 7). This is particularly demonstrated through the common use of pink as denoting the 'feminine' within the national breast cancer campaign (National Breast Cancer Foundation (NBCF, 2021; BCNA, 2021). This pink branding of research and care agencies for breast cancer also appears in other countries (American Breast Cancer Foundation, <https://www.abcf.org>; Breast Cancer Now UK, <https://breastcancernow.org>)

The two men diagnosed with breast cancer that I included in my Honours research, Rob Fincher and Rod Ritchie, became the catalyst for this doctoral research as male breast cancer appeared to be a gap in this field of research. This initial research premise was substantiated by the National Breast Cancer Foundation (NBCF), the national body for breast cancer research, with the CEO making the following statement:

The rarity has resulted in a lack of male breast cancer specific national or international research and as a result little is still known about male breast cancer with all treatment taken from knowledge attained from female breast cancer studies, which is not ideal. (NBCF 2016)

My researcher position within this project is that I am a breast cancer survivor and, as such, I am part of the breast cancer cohort. To an extent, I can claim agency for breast cancer patients, though my experience may be different to a male patient. In the literature on Autoethnography, one of the methodologies that I will be applying in my project, Pike (cited in Beals et al. 2019, p. 594) describes researchers as being *insiders* or *outsiders* of a cohort of participants. I assert that I am both; as a survivor I have a shared experience of the disease and as such am an *insider*. However, being female, my experience may have been different to that of a male, so in this context I am an *outsider*. It is through a common experience of breast cancer with my participants in this research that my research bridges the gap between *insider* and *outsider* (la Grange 2005, p. 126).

There are some researchers, like myself, who are both *insiders* and *outsiders* and as such have a non-binary research position. Psychologists, Sue Wilkinson and Celia Kitzinger (2013, p. 251) describe how researchers who had the same life experience as their participants are considered an *insider* to the group they were investigating. It is through this common experience that the researcher may gain data collection that may otherwise be excluded from an *outsider* researcher (Wilkinson & Kitzinger 2013, p. 252). Wilkinson and Kitzinger (2013, pp. 251-252) further describe how some researchers may not possess the same cultural experience as their participants, they could show a level of empathy but may not have experienced the same extent of trauma as their participants. As a female, and one included in the national breast cancer screening program, I am afforded some privileges that men do not currently have, and as such, I also inhabit an *outsider* status in this research. For example, I was diagnosed with breast cancer through Breast Screen, a public breast cancer screening service, as I was 47 and female. My diagnosis was provided as a free service where a male patient is not entitled to this.

My non-binary research position means that I have a level of rapport with the male participants in this research. Fortunately, both principal participants within this doctoral project have been eager to share their experience as they had previous knowledge of my work and knew that my current artwork aims to advocate for male breast cancer awareness. It is through this artistic connection with my principal participants, that I was able to develop an ongoing research relationship with Rob Fincher, now through his widow Ann Fincher, and Rod Ritchie. I was fortunate that Rob Fincher and Rod Ritchie consented to my video recording of their experiences of breast cancer. This has enabled me to document their observations of any changes in male breast cancer awareness through vignettes of their experience between 2015 and 2019. I also analysed written stories of male breast cancer patients, publicly available on the Male Breast Cancer Coalition (MBCC) website. I contacted the MBCC administration who were willing to share their resources with me, as I have shared some of my artwork with them and have attended some of their online forums. While the MBCC website is published in the US, the stories recorded are

from men all over the world including Australia. It is a vast resource and continues to be added to as more men are diagnosed. I analysed stories from the MBCC website to verify or refute the data from my video recordings of Rob Fincher (pers. comm., 2016, 14 February) and Rod Ritchie (pers. comm., 2015, 11 September; 2019, 27 November). The use of existing written stories on this website enabled my access to data that I would not have achieved as men are reluctant to share their experiences of breast cancer with researchers (R Ritchie 2019, pers. comm., 27 November, p. 11).

Knowledge of male breast cancer is scant (Midding et al. 2018), in terms of financial support for breast cancer patients, there is a divide according to gender (R Ritchie 2019, pers. comm., 27 November; < www.health.gov.au/initiatives-andprograms>). This divide could possibly impact on the health outcomes for transgender or intersex patients as well as men (Dhand & Dhaliwal 2010, p. 159). The language, visual icons, stories, and promotion of breast cancer within the media rely heavily on female protagonists and the disease is female stereotypically by its representation in "pink" (Koller 2008, p. 402). Discretionary aims of this research are to create an inclusive model where all gender identities are represented in the breast cancer narrative and to advocate for the diversity of patients.

#### 1.3. Central research and purpose of study

This research responds to the challenges of the current pink branding affiliated with breast cancer, as promoted by Australian health agencies such as the National Breast Cancer Foundation (NBCF) and Breast Cancer Network Australia (BCNA), and international agencies such as America Breast Cancer Foundation. My project intends, first and foremost, to create a platform where through visual and oral storytelling both female and male patients' issues are heard equally, coherently and in harmony. Central to this purpose is to allow male breast cancer patients to be given agency through greater public visibility and to allow their voices and stories embedded in their personal experiences to be heard. My practice-led research is based in visual and oral storytelling, I engage in a diversity of modalities as this allows for a variety of multi-sensory experiences to emerge, over time, to interrogate the research question and discover about the male breast cancer experience. The creative outcomes in this research explore and include video, audio, watercolour painting, textile sculpture, printing plates, embossed printing, illumination drawings,

artist journals and a coding journal. The use of diverse materials and performative expression can symbolically reflect the tactility and embodied experience of the disease; it has a physical manifestation on the bodies of breast cancer patients. By exhibiting a diversity of bodies with breast cancer, I employ strategic applications of artistic concepts, materials and processes that emerged in my arts practice throughout my doctoral study. The theoretical, conceptual and creative underpinnings that emerge from this study allow the viewer to renegotiate their own understanding of the disease. In considering this premise, this emergent research is prompted by the central questions:

To what extent might artworks in the forms of visual and oral storytelling subvert the current breast cancer awareness paradigm and provide an alternative multi-modal and experiential artistic platform that gives visibility and voice to male breast cancer patients?

Subsequently, I further ask: In what ways can my creative practice advocate for inclusive breast cancer narratives within the broader art and medical communities?

To provide alternatives to the current representation of men with breast cancer in visual and oral storytelling I have taken a two-pronged approach: a) to analyse stories of male breast cancer experience and allow for artworks to emerge from this analysis, and b), to be inspired to create artworks based my own reflexive arts practice. I have searched for alternatives to the perpetuation of the current awareness paradigm to find theoretical models such as Crip Theory (McRuer, 2006) and Inclusion (Butz & Besio, 2004) which may assist in altering or changing the perception that breast cancer belongs to women only. I have also reviewed artists, both historical and contemporary, such as Audrey Lorde (America), Louise Bourgeois, (France), Rosemarie Trockel (Germany), Annette Messager, (France), Jo Spence (Britain), Matuschka (America), Hanna Wilke (America), David Jay (America), Dan Elborne (Australia), Haya Cohen (Australia), Ann Hamilton (America), and Janine Antoni (America), to ascertain how they used artistic strategies to subvert dominant ideology through their application of materials and methods to create artworks. The project's further purpose is to create a body of artwork that speaks to a wider audience including medical practitioners, patients and their families, and breast cancer awareness advocates, of the need for more inclusive narratives of breast cancer awareness. As awareness of male breast cancer is low (E Whiteside 2017, pers. comm., 17 November), exhibition of the artworks and promotion through breast cancer agencies, media and social media may inform others about the disease and its existence in men. As Whiteside (2017, pers. comm., 17 November), breast cancer medical researcher, explains male breast cancer survival is lower than women's and raising awareness is vital to facilitate earlier diagnosis.

#### 1.4. Theoretical scope of study

Although the creation of artworks is the principal investigatory approach of this research, it has received 70% of my time and efforts in this Doctor of Creative Arts (DCA). The focus of this study is to make artworks that create knowledge about men with breast cancer, to raise awareness of the diversity of people with the disease. From a theoretical viewpoint, my research considers fields other than the arts to find a basis to analyse the current effectiveness of breast cancer awareness and search for explanations why men may be excluded from images and dialogue about breast cancer. I explain men's experiences in terms of theoretical underpinnings of contesting masculinity, transgressive bodies, marginalisation, othering, emotional, physical and or psychological trauma.

The Literature Review (Chapter Two) also informs my emerging artworks through the contemplation of strategies from Crip Theory (McRuer, 2006), and inclusive representation from Niall Richardson (2016) as well as David Butz and Kathryn Besio (2004), researchers in human geography. Crip Theory pertains to people who are *othered* because they transgress societal norms, this theory provides strategies that were pivotal in this research, and it provides an insight into how assumptions in society may be destabilised. Male bodies in breast cancer transgress the assumption that it is a women's disease (Richardson, 2016) and this research explores strategies from Richardson (2016) and Butz and Besio (2004) to counter the gender stereotyping of breast cancer and suggest inclusive models of representation of the disease. The process of integration of the research question and the creative outcomes that emerged from this research in response are outlined in the chapters of this exegesis.

#### 1.5. Overview of the methodological approach

This research is qualitative, as it interrogates written and oral recounts of male breast cancer experience (Hammersley 2013, p. 1). As my arts practice involves documenting experiences of breast cancer, reading stories from male breast cancer patients and articulating my research from the literature review into artwork, it is practice-led research. As Graeme Sullivan (Smith & Dean 2009, p. 4) art theorist explains, practice-led research can be conducted independent of creative work; it can include the shaping of creating artwork; documenting, theorising or contextualising created artwork; and/or the process of creating artwork. This practice-led study's methodological approach is based on the use of genuine Authoethnographical representations of men with breast cancer in video recordings by me and written stories from a published website – MBCC (2021).

Drawing on Autoethnography, a research methodology that enables personal experiences to describe and critique cultural beliefs (Adams et al. 2014, p. 1), I reflect on my own experience to collect and collate stories about male breast cancer as a means of critiquing the medias' and Australian health agencies' branding of breast cancer awareness as pertaining to the feminine.

As there is little knowledge about male breast cancer, I engage Grounded Theory as a methodological approach to encourage new knowledge to emerge during my practice-led research (Charmz 2008, p. 115). Grounded Theory is a systematic and inductive approach to collecting and analysing data; there are no preconceived ideas and no hypothesis. Within this research, I used a methodological model of coding to find theoretical categories and collated supporting evidence for each category. Specifically, I use Grounded Theory coding guidelines (Charmaz 2008, p. 163) and adapt these to analyse the stories I had documented in video or read on the Male Breast Cancer Coalition website (MBCC 2021). The coding guidelines from Grounded Theory as specified by Kathy Charmaz (2008), developer of constructivist Grounded Theory, were adapted into artworks where I found common links which explore my question of why men are excluded in breast cancer images and dialogue. Grounded Theory demands multiple data sets, and mine include: written stories by male breast cancer patients; documentation in video of participants' stories; photographs of patients; artefacts inspired in response to interactions with participants; artworks created from analysis of collected data sets; readings from medical journals and facts from breast cancer agencies related to male breast cancer. It was through analysing the video transcripts and reading in total 167 male breast cancer stories, from Australian and overseas patients, I more thoroughly understood the marginalisation of men with the disease. I then set about searching for strategies to include men in imaging and dialogue about breast cancer and articulated my findings in representational text and artworks for public exhibition.

This project was conducted using the protocols of USQ's Human Ethics Approval H19REA060 which was approved on 29 April 2019, H19REA060 (v1) which was approved on 14 December 2020 to include Rod Ritchie's ultrasounds and again H19REA060 (v2), which was approved on 17 June 2021, to include a pre-study video and photographic work. A further rationale for using Autoethnography and Grounded Theory methodologies are explained and expanded on in Chapter Four. A discretionary aim of this research is to provide a methodological approach which may be used for other marginalised groups, particularly where participants may be reluctant to share their experience.

Although my focus is on male breast cancer, I decided to include some of my earlier video and photography of women with breast cancer along with the male images and dialogue. The rationale for this came from Rob Fincher's (2016, pers. comm., 14 February, p. 21) interview when he said, "we are all part of the same health issue". It is a tenet of my arts practice to be inclusive and respectful of all perspectives, also by excluding the female representation would have been akin to the exclusion of the male image and voice in the representation of breast cancer. My central aim is to create a body of work that acknowledges the diversity of people diagnosed with breast cancer.

#### 1.6. Chapter overview

The aim of this chapter (Chapter One) is to provide an overview of the central research in terms of its aims and purpose of bringing awareness to the diversity of breast cancer patients as well as the theoretical, conceptual and methodological approaches which inform my arts practice. In Chapter Two, I discuss the theoretical underpinnings that I used to anchor my practices to glean strategies on how I might challenge the notion that breast cancer belongs only to women. Drawing on the seminal theoretical discourses of Diane Price Herndl (2006), American Professor of Women's and Gender Studies, who discusses the entrenchment of breast cancer in the media as being feminine, I look at the context of breast cancer awareness and how marketing the disease in pink, visually, is doing a disservice for male patients. Through the seminal texts of Evamarie Midding et al. (2018), German medical practitioners, I discuss how men with breast cancer feel socially stigmatised. By referring to Raewyn Connell, Australian sociologist known for the concept of hegemonic masculinity, I discuss the concept of masculinity and how the stereotyping of breast cancer as feminine is in opposition to hegemonic masculinity. I consider Richardson's (2016) Transgressive Bodies Representations in Film and Popular Culture and assert that men with breast cancer are a transgressive embodiment of breast cancer and disrupt the assumption that it is a female disease.

According to Thomas (2010), men with breast cancer are a minority cohort. I consider Sarah Maria Halbach et al. (2020), medical practitioners, who explain that being a minority and coupled with contested masculinity, men with breast cancer feel marginalised and *othered* in social as well as health care settings. Drawing on Tom Donovan and Maria Flynn (2007), cancer nurses, I explain how having a female stereotyped disease is distressing for male patients and leads to trauma. I consider the tropes of *Crip Theory: Cultural signs of queerness and disability* (2006), where Robert McRuer, American theorist, suggests that "coming out" is a strategy to destabilise dominant assumptions in society. This is supported by Alia Sheikh (2008) clinical psychologist, who affirms the therapeutic value of self-disclosure. Men with breast cancer, however, are reluctant to share their experience as having the disease is a source of social stigma (Halbach 2020; Midding et al. 2018). Julia Kristeva (1982, p. 5), Bulgarian-French philosopher, explains self-abjection as the revulsion of self, in this study it refers to the distancing of men from having a "women's

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disease", and I connect this concept to the reluctance of men to come out with their experience. I explore ways to raise awareness through sourcing material where men do share their experience in the "safety" of an online male support group Male Breast Cancer Coalition (MBCC). To address the challenge representing men with breast cancer, I also engage with the suggestions of Butz and Besio (2004), who outline strategies to collect and collate Autoethnographical representations of a minority cohort and assimilate it with idioms from the dominant culture. I consider this strategy to articulate in artworks an inclusive representation of people with breast cancer.

In light of the project's outline and discussion of key theoretical underpinnings, Chapter Three involves a review of historical and contemporary artists that inform how artists use their practice to subvert societal norms and depict sensitive subjects. Firstly, I explored French sculptor Louise Bourgeois (b. 1911), the German conceptual artist Rosemarie Trockel (b. 1952) and the French artist Annette Messager (b. 1943) to interrogate how they used their practice to critique societal norms by challenging entrenched modes of perception in patriarchal society through material selection and artistic processes. In light of the multimodal approaches within my own work, my artist audit includes creative practitioner's more broadly, such as the American poet and activist Audrey Lorde's *The Cancer Journal* (1980), which is a self-disclosure of her own experience of breast cancer; this book challenges, as she describes, the "silence and invisibility" of the disease (Bolaki 2001, p. 1). I argue that historically, breast cancer has been a taboo subject, but through the activism of feminist artists such as British photographer Jo Spence (b. 1934) breast cancer has entered the domain of public dialogue. This is particularly made further prominent by contemporary American photographer Matuschka, her image *Beauty Out of Damage* (1993) was published on the cover of The New York Times, it broke the breast cancer topless taboo in the media. Matuschka's image *Beauty Out of Damage* (1993) was also published internationally and is still in demand, this image was pivotal in raising awareness and acceptance of female breast cancer in the public domain (Peterson & Matuschka, 2004).

I review artists both historical and contemporary to find strategies that may be used in a multi-modal arts practice to subvert the current paradigm of awareness. Through the lens of photography, I reviewed artists such as Hanna Wilke (America) and David Jay (America) from an *insider* and *outsider* perspective. I also refer to two Autoethnographical representations in video artworks from men with breast cancer (MBCC 2021) to see how they would prefer to be represented. Exploring how artists use their practice to articulate sensitive subjects I reviewed two Australian sculptures, Dan Elborne's *One Drop of Blood* and Haya Cohen's *Alchemy* (2011), as both artists are outsiders who depict breast cancer in metaphorical images. Although Ann Hamilton, American installation artist, does not depict breast cancer, her installations were pivotal as she is a multimodal artist like myself and depicts sensitive subjects. Finally, I refer to Janine Antoni, American multi-disciplinary artist, as the aim of her sculptural series *Milagros* (2015) inspired me to consider artworks as a modality of healing. The aim of the artist review was to glean strategies to engage viewers of the artwork, to glean choices of materials and processes that may be articulated into my own artworks.

Chapter Four outlines the methodologies used in this research and provides a rationale to the selection of Autoethnography (Ellis, Adams & Bochner, 2010) and Grounded Theory (Charmaz, 2008). A central artistic process for this research was to use calligraphy to document the analysis of data sets; the analysis of video transcripts and written stories from the Male Breast Cancer Coalition website are contained in my Coding Journal (2020-2021). The representational text analysis from my artwork created during the research period, was also documented in calligraphy, and is in my Artist Journal (2021). As a way of contextualising why I have adapted these methodological approaches to analyse the male breast cancer patient stories, I explain my interpretation of Autoethnography and Grounded Theory, and show how this is applied in artworks to articulate my data analysis. I have tabled the time frame for the data analysis (See Table 4.1 Chapter Four); I tabled the time frame for the creation of artworks that emerged and developed; I included the timing for exegesis writing and exhibition of artworks (see Table 4.2 Chapter Four). These tables also outline the diversity of methods I have used in my practice-led research to provide a rigorous investigation into the effects of the current breast cancer paradigm on male patients. As a practicing artist, I have created artworks for public exhibition as one aim of this research is to raise awareness of the diversity of people with breast cancer.

Chapter Five addresses the findings of this research in terms of artworks created. In this chapter, I begin by explaining that there is a distinct lack of knowledge about male breast cancer. The lack of knowledge is in awareness of the disease in men and also the lack of knowledge in the medical field, as treatment for breast cancer is based on women's studies. I articulate how I share this knowledge through the creative outcomes of knitted breasts in *Standard* (2018-2021) and calligraphy in my *Coding Journal* (2020-2021). I elaborate about how I use an emergent artmaking process through data analysis using Grounded Theory coding and applied it to genuine Autoethnographical representations (male breast cancer stories) to create the *Illumination* (2021) and *Stereotype and Flong* (2021) series. These creative outcomes are the direct translation of Grounded Theory coding into artworks and as such are significant as my contribution to the arts field. In this chapter I also explain the emergence of my artistic practice of *illumination* as an interactive artwork, which is a counterpoint to the artist concept of *erasure*.

Finally, I offer alternative strategies to the current paradigm of awareness drawing on the strategies from Crip Theory (McRuer, 2006) and Inclusion (Richardson, 2016; Butz and Besio, 2004) to counterpoint the current paradigm of awareness and advocate for male-specific medical research. I explain in this chapter how I implemented strategies gleaned from my artist review that create subversion and engage the viewer of the artworks so that they may renegotiate their understanding of breast cancer. I reference the use of specific materials and modalities in art that best describe how men with breast cancer feel being a minority. Some of the artworks were informed by theory and other artists' practices, as alternatives, to counter the assumption that breast cancer belongs only to women. In each artwork or series of artworks, I aim to explain the choices in terms of materials, processes and artist concepts which were gleaned in the artist review (Chapter Three, Section 3.5). I also explain the strategies that were used to create counterpoints to the assumption that breast cancer is a "woman's disease".

Chapter Five also contains concluding remarks and future recommendations. I explain how some artworks have been shared with breast cancer agencies such as the National Breast Cancer Foundation and Breast Cancer Network Australia, as well as the sharing of resources for medical institutions and medical practitioner's offices.

The new knowledge and contributions of this research are explained in terms of the application of the methodological approach, the direct application of data analysis through Grounded Theory coding, into creative outcomes. Finally, I make observational points about visual and oral storytelling of male breast cancer and make suggestions for future investigation.

# **CHAPTER TWO: LITERATURE REVIEW**

Drawing upon the interdisciplinary fields of visual arts and health, the purpose of this chapter is to address seminal theoretical, conceptual and contemporary art discourses that consider male breast cancer and the need for greater societal awareness and more accurate and alternative visual representations of the illness that is currently being depicted by key national health campaigns and broader media (BCNA, 2016). In this chapter, I will explore the challenges men face when they experience breast cancer, often drawing on direct individual male experiences as primary data. This strategy is firstly to give voice to the marginalised as well as a means of responding to the limited literature pertaining to this topic. In turn, I will introduce the context of male breast cancer in relation to the current paradigm of awareness in images and stories that are common in the mainstream media portrayal of breast cancer and give the impression that it is a female disease.

Seminal theoretical discourses such as *Men with a "women's disease": stigmatization of male breast cancer patients – a mixed methods analysis*, Midding et al. (2018) discusses that male patients may experience social stigma; while Thomas (2010) explains that breast cancer may contest a man's sense of masculinity. Male bodies with breast cancer transgress the assumption that it is a women's disease (Richardson, 2012). In doing so, some men experience marginalisation (Gedro & Mizzi, 2014) and/or othering (McQuarrie, 2009) as well as trauma (Leys, 2000). Some men respond to a breast cancer diagnosis by concealing their disease (*Coding Journal* 2020-2021, p. 56-57); men are generally reluctant to make public their diagnosis and the consequence is that male bodies with breast cancer are rarely if at all seen (BCNA, 2016). Importantly, male protagonists who talk about the disease, naming it as "breast cancer" are virtually non-existent in mainstream media, so the stereotype of breast cancer belonging only to women continues to persist (BCNA, 2016; Herndl, 2006).

A central concept underpinning this literature review, is my assertion that male bodies are a transgressive embodiment of breast cancer (Richardson, 2016). I assert that male breast cancer experience, by comparison to females, is abject (McCabe, 2010) and marginalised (McQuarrie, 2009) which leads to trauma (Leys, 2000) for some patients. I have chosen to focus on these theoretical areas because male bodies with breast cancer disrupt the stereotypical representation of the disease used in images and stories from the mainstream media, from the icons associated with the disease to the décor of the medical treatment rooms. The interconnected marginalisation between the lack of images of men with breast cancer and stigmatisation of males' experience, is a central anchor for my practice, assisting in interrogating the research question from both a theoretical perspective and in my artmaking and production.

The theoretical exploration undertaken in this chapter aids my process of refining my research questions and the strategies that might create a change in future perspectives concerning broader breast cancer narratives. A strategic approach in this investigation is to find theoretical underpinnings that might counter the negative consequences for male patients. In this chapter, the concept of masculinity is explored via the seminal texts such as *Hegemonic masculinity: Rethinking the* concept (Connell & Messerschmidt, 2005), I explore the need to advocate for men with breast cancer as outlined in the BCNA Consultation Report *Meeting the needs* of Australian men diagnosed with breast cancer (2016) and consider the underpinning of What makes a man a man? The lived experiences of male breast *cancer* (Donavon & Flynn, 2007). The theoretical underpinnings contained in *Crip* Theory: Cultural signs of queerness and disability (McRuer, 2006) are explored to ascertain strategies to represent male bodies with breast cancer. While intersex, transgender males and females with breast cancer are not a focus of this study, McRuer's (2006) insights offer a wide application for the inclusion of all-genders as none are immune from breast cancer diagnoses.

# 2.1. Challenges of men with breast cancer: The Pink Ribbon campaign

The challenge for males with breast cancer is the dominance of female-related imagery and protagonists in the depiction of the disease in the mainstream media. To understand how the concept of breast cancer as "belonging to women only" is embedded into society, my literature review begins with exploring the historical background to the Pink Ribbon Campaign of breast cancer awareness and its implications for men with breast cancer. The Pink Ribbon Campaign began in 1991 when Charlotte Haley made apricot-coloured ribbons and attached messages as a fundraising venture for breast cancer research (Theobald 2012, p. 12). Following from Haley's grassroots efforts, the Pink Ribbon Campaign was marketed in America when cosmetic company Estee Lauder put a pink ribbon on their products and donated a percentage of their profits to breast cancer research (Theobald 2012, p. 12). Breast cancer is marketed in pink; the logos for the national breast cancer agencies for research and advocacy are pink. By 2018, the Australian National Breast Cancer Foundation (NBCF) logo was rebranded with a pink and darker reddish pink logo and community feedback was sought about the new logo (NBCF 2017-2018, p. 15). The rebranding came about as the NBCF did not wish to be confused with other pink charities. Sydney based branding agency RE (part of the M&C Saatchi group) designed the logo as pro-bono support for the NBCF (NBCF 2017-2018, p. 14). The Breast Cancer Network Australia (BCNA) is represented by a logo of a pink woman (BCNA, 2021).

Pink is the colour associated with breast cancer research and awareness globally, however, the colour pink is problematic as it represents the feminine in western culture (Koller 2008, p. 395). The Breast Cancer Network Australia (BCNA) Consultation Report (2016) found that Australian men diagnosed with breast cancer often feel excluded from breast cancer awareness campaigns, because the colour pink does not represent them. The consequence is that the male patients are not represented in public logos. Australian agencies for breast cancer research and advocacy have excluded the "blue", or the male representation in their logos (BCNA, 2016; NBCF, 2017-2018). The correlation between men's lack of visibility in images and stories represented in the public media reasonably perpetuates the notion that breast cancer belongs only to women. As Donavon and Flynn (2007, p. 465) explain, literature relating to male breast cancer is scant. Men diagnosed with breast cancer experienced symptoms of stress emerging from their response to shock and body image (Donovan & Flynn 2007, p. 465). The shock of diagnosis may be linked to the notion that masculinity is in opposition to femininity (Donovan & Flynn 2007, p. 467). As Thomas (2010, p. 32) noted, 79% of men in her study were unaware that men could get the disease, while 43% stated that they would question their masculinity if diagnosed with breast cancer.



Figure 2.1: National Breast Cancer Foundation Original Logo (1994) Source: https://nbcf.org.au/25years/



Figure 2.2: *Rebranded National Breast Cancer Foundation Logo* (2018) Source: https://nbcf.org.au/25years/

Supporting the concept that breast cancer only belongs to women is the promotion of the disease by women who "come out" with their diagnosis of breast cancer. Celebrities such as Kylie Minogue, and Angelina Jolie heralded awareness of breast cancer and genetic breast cancer and were celebrated for their bravery in doing so (Lebo et al. 2015, p. 3959). But when Nick Greiner, former NSW premier, came out with his breast cancer diagnosis, it made little headline news (R Fincher 2016, pers. comm., 14 February). As Rob Fincher (cited in BCNA 2016, p. 15), breast cancer patient who is now deceased, explained "I think it's about the messaging. And I think it's about just making sure that we're not invisible and not hidden. So, some way of sort of raising that up a level". The consequence of being hidden, as Rod Ritchie (cited in BCNA 2016, p. 15), male breast cancer survivor, says "is the lack of awareness. I still think that there's an ignorance out there in the general public". The same BCNA Consultation Report *Meeting the needs of Australian men diagnosed with breast cancer* (2016) found that giving male breast cancer more visibility would also help alleviate stigma and help men to feel supported. This report also

highlighted key issues which included the lack of awareness and understanding of male breast cancer patients among some health professionals (BCNA 2016, p. 15). I interrogated possible medical reasons why men have a poorer prognosis, to evaluate whether this was due to lack of awareness or any other medical reason, this is discussed in Chapter Five, Section 5.2.

# 2.2. Theoretical underpinning: Social stigmatisation and its effect on raising male breast cancer awareness

Male bodies are rarely seen in breast cancer visual material for fundraising and promotion of the disease leading to lack of awareness of the disease in men (BCNA, 2016). As Halbach et al. (2020, p. 29) in Male breast cancer patients' perspectives on their health care situation: A mixed-methods study, explain awareness needs to be increased to alleviate stigmatisation for male patients. Donovan and Flynn (2007, p. 467), argue that breast cancer is associated as belonging only to women. Alia Sheikh (2008, p. 90), psychologist, states that "coming out" with the disease should ideally increase visibility of men with breast cancer. There is still a perceived need for men with breast cancer to be included "in consumer representation groups, and proportionate level of visible representation of male breast cancer e.g.: through social media, awareness campaigns and fundraising events" (BCNA 2016, p. 17). The barrier for this happening is the hidden stigmatisation among male breast cancer patients: the body shame, feelings of emasculation and the fear of other people's reactions (Midding et al. 2018, p. 2198). This stigmatisation manifests in the male concealment of breast cancer and men rarely sharing their experience publicly; some men do not show their bare chests in public to avoid the raised eyebrows and stares (Barnes cited in MBCC 2021). As Ritchie, a male breast cancer survivor describes, men need to feel comfortable to "come out" about their disease (Ritchie, R 2019, pers. comm., 12 September, p. 11).

Added to the exclusion of male images in mainstream media, is the stigmatisation some men have experienced in cancer-care settings. Most breast cancer care centres are set up for women, adorned in pink and with images of women. Men are treated like outsiders and excluded from access to some services (Midding et al. 2018, p. 2203). Breast cancer care facilities are often female engendered, as Bret Miller (cited in MBCC, 2021), breast cancer survivor and founder of the Male Breast Cancer Coalition explains, he was confused that his screening was at a "Women's Hospital". This stigma leads to the reluctance of men to share their experience and in turn raise awareness of male breast cancer (R Ritchie 2019, pers. comm., 12 September, p. 11). The consequence for male patients is that breast cancer can contest their engendered self, it can be seen as an assault on their sense of masculinity (Donavon & Flynn 2007, p. 464).

#### 2.2.1. Challenging hegemonic masculinity

In Connell's theory of masculinity, its origins and influences on the study of gender, Raewyn Connell (cited in Wedgewood 2009, p. 332), an Australian sociologist known for the concept of hegemonic masculinity, explains that the notion of masculinity is a social construct: it is the patterns of actions and beliefs that define the overall gender order in society. The Bulgarian French feminist psychoanalyst, Julia Kristeva, refers to gender difference as being the power relationship between men and women in a patriarchal system (cited in Gambando 2014, pp. 148-9). The philosopher and gender theorist Judith Butler (2005, p. 79), explains that gender identity is established through behaviour. Connell (cited in Wedgewood 2009, p. 335) describes multiple forms of masculinity, but hegemonic masculinity has traditionally been at the top of the hierarchy which she still entrenched in society. According to British sociologist, Jeff Hearn (1992), the notion of hegemony is directly linked to dominance over history. This is exemplified when he states that hegemony relies on consent of some men:

in a very different way, the consent of some women to maintain patriarchal relations of power. At least some powerful men are dominant in the construction of women's consent and the reproduction of men's consent. (Hearn 1992, p. 51)

Connell and Messerschmidt (2005, p. 833) link this premise to patriarchy and the behaviours of this masculinised culture to highlight males performing their role as being confident, focused on the job and ruthless, where they conceal their emotions. The prestige of social power is linked to this idealised form of masculinity, particularly in institutions such as government and corporations where men continue to hold the majority (Robinson et al. 2008, p. 136). The field of masculinity studies seeks to engage with and represent men who do not subscribe to the hegemonic or toxic masculinity that is produced through ongoing patriarchy which can subordinate non-hegemonic males. According to Hearn (1992, p. 51), critical studies on men and masculinity reveals a complex interplay of difference between men within a patriarchal system.

Breast cancer is stereotypically linked to women and has carved a niche in the medical industry which is governed by hegemonic masculinity in the diagnosis and treatment of cancers. Connell (cited in Wedgewood 2009, p. 332) explains that hegemonic masculinity is often understood as being in opposition to femininity and hence men distance themselves from appearing feminine. Therefore, men with breast cancer even if they are not hegemonic males, suffer from being invisible in this paradigm. The consequence for a man diagnosed with breast cancer is that he may feel a loss of masculinity as his place in the social hierarchy may appear to have been demoted or placed in the company of a disease dominated and defined by women's narratives (Donovan & Flynn 2007, p. 466).

The focus of breast cancer as a female disease has meant that the Australian health system is biased towards women. According to Connell and Messerschmidt (2005, p. 831) gender relations are represented as dichotomous, and this is reflected in terms of health policy and programs. Free breast screening is available to women between the ages of 40 and 75 in Australia, but men regardless of hereditary breast cancer are exempt (Breast Screen Australia 2021). For example, Rod Ritchie (2019, pers. comm., 12 September, p. 11), explains that his identified familial breast cancer resulted in his daughter receiving medical attention through surveillance as a possible candidate for the disease, but his son was not eligible to receive the same service as he did not meet the criteria of being female. Due to the gender stereotyping of breast cancer, men are unaware of the need to look for changes in their breast health (BCNA 2016, p. 7). The consequence for men, in regard to their lack of awareness, is that they are generally diagnosed with later stage breast cancer (Whiteside 2017, pers. comm., 17 November) making them potentially "at risk" of long-term disabling conditions (<https://www.cancervic.org.au>).

The prevailing issue is that other cancers are given a name, such as melanoma, are without a gender distinction (Melanoma Patients Association 2021). The term

"breast" is correct in that it refers to the mammary gland in all human beings. The focus of this research is to describe breast cancer as "genderless" and to establish the need for inclusivity in how the disease is represented and addressed in the media as well as clinically managed within the health sector. This research focuses on valuing marginalised masculinities through male breast cancer stories. Donovan and Flynn (2007, p. 468) explain that a strategy to help men come to terms with the disease is by "coming out" as a cancer patient and sharing stories of their experience. While BCNA (2016, p. 15) also explains there is a need for more images and stories of men with breast cancer to destigmatise the male experience. Although advocacy for male breast cancer is increasing, particularly with global support networks such as the Male Breast Cancer Coalition (2021) with some breast cancer agencies beginning to recognise and accept male patients, men generally remain an anomaly, with women being the major stakeholders in breast cancer (R Ritchie 2019, pers. comm., 12 September, p. 10).

#### 2.2.2. Male bodies: Transgressive embodiment of breast cancer

Richardson (2016, p. 1) explains how transgressive bodies challenge the "norm"; for example, a male body with breast cancer is currently a counterpoint to the message of breast cancer and, until recently, has remained absent in the representation of the disease. The consequences of being a minority within a female cohort is that men with breast cancer have minimal or no representation in public images of breast cancer or in logos depicting the disease (BCNA, 2021; NBCF, 2021). I induced, through my Honours research, interviews with male participants that they felt isolated (Baker, 2016). This "absence" provided me with a topic for this DCA project and reinforced the necessity to address male breast cancer as a central premise within my research project.

Within this research context, the transgressive bodies in breast cancer awareness paraphernalia are male images and stories (and their absence). In Richardson's *Transgressive bodies representations in film and popular culture* (2016, p. 172), he describes transgressive bodies as those that cross the boundary of the "natural order of things" or the "norm". The definition of "norm" relates to the dominance of heterosexuality and able-bodiedness in society (McRuer 2008, p.2); Richardson (2016, p. 166) considers the representation of the non-normative body in contemporary culture such as film, television, and the internet. This research contemplates these modalities as contemporary forums for promotion of breast cancer awareness. This is particularly so, as "non-normative bodies" are represented in popular culture either as "freaks" for entertainment or in an aggrandised mode where there is acceptance because they are viewed as upstanding or socially prestigious (Richardson 2016, pp. 5-6). An example of an aggrandised mode in breast cancer was the public "outing" of Angelina Jolie's double mastectomy as a preventative strategy for people who carry the BRCA gene, an abbreviation of Breast Cancer (BRCA), and who are at risk of developing the disease (Lebo et al. 2015, p. 3959). This indicates that the power of contemporary modalities in visual and oral storytelling may be dependent on the use of "normative" high-profile female media celebrity advocates to promote awareness of the disease.

Male images and stories about their experience of breast cancer have been lacking, because of marginalisation and abjection of male bodies with the disease. The distinction comes from the definition of abjection as a horror or revulsive feeling when faced with someone or something, which is radically excluded (McCabe 2010, p. 214). As breast cancer awareness was embedded in society as feminine (Hess & Melnyk 2016, p. 1551) male bodies with breast cancer have been relegated to selfabjection. Kristeva (1982, p. 5) describes self-abjection as when someone is opposed to themselves and discusses how an ordeal can cause someone to self-abject so "they are no longer seen in their own right but forfeited, abject". A diagnosis of breast cancer can contest a man's sense of masculinity (J Boyages, 2021, personal communication, 1 March) and in turn, men with breast cancer may self-abject. This premise can be aligned with the findings of Thomas (2010, p. 37), she explains that 43% of men in her study said they would feel an assault on their engendered self, if given a diagnosis of breast cancer. Male bodies with breast cancer transgress the border of the assumption that it is a feminine disease, compounded with this is the reluctance of men to share their experience as it can produce an abject sense of shame on their sense of masculinity (Thomas 2010); they are therefore, commonly silent about their experience (Donovan & Flynn 2007, p. 464). A man diagnosed with breast cancer "enfreaks" the hegemonic male body (Richardson 2016, p. 177), as the disease is stereotypically female. Their presence is marginalised and relegated

to a lesser importance than their female counterparts; this *othering* adds to the shock of diagnosis and contributes to patient trauma.

#### 2.2.3. Marginalisation: Otherness and trauma

Marginalisation relies on the presence of a dominant culture or "order" (Gedro & Mizzi 2014, p. 446), in the case of my research, it is the assumption that it is a female disease which is perpetuated through its visual images and stories. Marginalisation in the context of this research focuses on the interrogation of *othering* (McQuarrie, 2009) and the consequence of marginalisation is trauma (Leys, 2000) for male breast cancer patients. Leys (2000, pp. 1-3) describes trauma as being psychological, emotional and/or physical, trauma stems from a disturbing experience, emotional shock or physical injury. In the context of this research *othering* is based on gender, where women fit the socially constructed category of breast cancer as a female disease and men are the often-marginalised others (McQuarrie 2009, p.636). *Othering* is achieved by exclusion or differentiation of male breast cancer patients in images and stories that promote the disease. A significant omission is in the logos used by Breast Cancer agencies where the images are engendered in pink, for example the NBCF logo is a pink ribbon (see Figure 2.2).

Many authors such as Angharad Valdivia (2017) and Jean Daniel Jacob et al. (2021) address *othering* as being a result of marginalisation through abjection and enfreakment, in this research *othering* is concerned with men with breast cancer. As Valdivia (2017, p. 134), explains *othering* may occur according to gender and sexuality; historically it refers to the marginalisation of women in patriarchal society. McQuarrie (2009) describes *othering* as a process of stigmatisation which defines another. While Jacob et al. (2021, p. 281) describes how exclusion is created by division between a dominant social group and the *others*. In this research, I consider that men are the marginalised *others* as the disease is associated with women (Robinson et al. 2008, p. 138). The consequence for some male patients is that they are faced with the trauma of having breast cancer that extend from feelings of being emasculated and alienated (Donovan & Flynn 2007, p. 465).

*Othering* may be a consequence for male breast cancer patients as the vast numbers of women in comparison to men emotes feelings of alienation (Halbach et al. 2020). Males are reluctant to being associated with breast cancer as it is promoted as belonging to women, for a man having the disease can contest their sense of masculinity (Thomas 2020, p. 37). Men may self-abject the disease as it has historically been dominated by women, pink branding and feminine protagonists who promote the disease in mainstream media (BCNA 2021; NBCF 2021). Male images and stories about male breast cancer are othered from the dominant culture, men's stories are effectively diminished or erased, as the prevailing assumption remains that breast cancer belongs to women.

Marginalisation of males with breast cancer is evident in health care facilities where they are either segregated from women or placed in women's facilities (Michael C cited in MBCC 2021). Briohne Sykes (B Sykes 2016, pers. comm., 9 March), a participant in my Honours research, explains how she saw one man in the radiation ward of about 100 women and often wondered how he felt; she observed that he looked so alone. Leys (2000) describes trauma as a sudden or unexpected emotional shock which can cause the victims to be haunted by intrusive memories of the event. John Robinson et al. (2008, p. 138) describes how men with breast cancer tend to feel alienated, compounded with this is their feeling of de-masculinisation. They may feel frustrated as they are associated with a disease commonly accepted as being feminine (Robinson et al. 2008, p. 136).

The idea of living with what is considered a feminine disease is distressing and stigmatising, and/or traumatic (Donavon & Flynn, 2007). In the survivor stories from the international support agency Male Breast Cancer Coalition (MBCC), based in the United States of America, Fincher (2016, pers. comm., 14 February), asked that it is called "chest cancer" to alleviate this stigma, however, as stated in Chapter One, I refer to breast cancer as anatomically "breast" is the correct biological name for the affected body part (Cancer Australia 2021). Steve Del Gardo (cited in MBCC, 2021), male breast cancer patient, created a video to raise awareness of male breast cancer in America and his foundation was named *Protect the Pecs* (2014); he refers to "pec" rather than breast. For some men they self-abject (Kristeva 1982, p. 5), they conceal their breast cancer diagnosis and/or remain silent (Donovan & Flynn 2007, p. 468) in turn this may cause trauma. Van der Kolk (cited in Leys 2000, p. 7) noted that trauma is preserved in the narrative memory, while Sheikh (2008, p. 85) found that

the coping strategy of self-disclosure through writing and talking assists in the cognitive processing of trauma and, in turn, brings meaning and significance to loss. A strategic approach in this research is to use the collected stories of male breast cancer experience to inform the creative work, I hope that this also allows for some healing for those who share their stories. To explore how this is possible, I refer to McRuer's Crip Theory (2006) focusing on the acceptance of the diversity of bodies that exist in breast cancer patients.

#### 2.2.4. Male breast cancer and Crip Theory

*Crip Theory* is based in a combination of disability studies and queer theory suggesting that society has constructed and embedded bias towards societal norms. The theoretical framework of Robert McRuer's (2006) *Crip Theory: Cultural signs of queerness and disability emerged* from cultural studies and questions societal norms, specifically he explains how able-bodiment and heterosexuality are dominant cultural systems. McRuer (2006) explains how these cultural systems are constructed and embedded in society, then questions the efficacy of these systems. Although McRuer's (2006) *Crip Theory: Cultural signs of queerness and disability* may not classify males with breast cancer as non-normative, men do not fit the stereotype of women with the disease, the intention of this research is to consider strategies from this theory that may be useful in approaching difference respectfully to raise awareness of men with breast cancer.

The basic tenet of *Crip Theory* is that all bodies are valid and should not be defined by their "ableness" or "sexuality"; McRuer's aim was to destabilise dominant assumptions that are taken for granted in our society (Goodley & Runswick-Cole, 2016, p. 1). By accepting the assumption that breast cancer is a feminine disease, society permits the established paradigm which may disadvantage people *other* than women (Herndl 2006, p. 239). This is evident in the higher mortality rate of male breast cancer patients compared to their female counterparts; although gay, intersex or transgendered statistics are scant (Cancer Australia 2021), the notion that breast cancer it is a genderless disease upsets the assumption that breast cancer strategies that challenge assumptions; in this research it is the assumption that breast cancer belongs to women. This assumption may be destabilised by honouring

diversity, by valuing the variety of identities that make up society. It is through the act of "coming out" or the visibility of difference, in the case of this study it is making visible male bodies with breast cancer (McRuer 2006, p. 16).

Donavon and Flynn (2007, p. 468) found that men with breast cancer who "came out" with their experience had better wellbeing than those who did not. Alia Sheikh (2008, pp. 85, 90) clinical psychologist, explored the therapeutic value of self-disclosure and noted positive outcomes where trauma could be changed to shifts in values and increased personal strength. It is by openly engaging with men with breast cancer, by engaging with their stories that this research may potentially create some healing and may create social change from an individual level to the broader community (Sumara & Robson 2016, p. 617).

## 2.2.5. Inclusive representation of men in the imagery of breast cancer

One strategy to assist acceptance of difference in society was suggested by Butz and Besio in *The value of Autoethnography for field research in transcultural settings* (2004). The researcher works partially in collaboration with the participants and appropriates idioms from the dominant culture (Butz & Besio 2004, p. 354). The underlining strategy is to collect Autoethnographical representations from research subjects; Autoethnographical representations can be written accounts of experience or may be other media such as photos, text or movies (Ellis, Adams & Bochner 2010). In the case of this research the dominant culture is female, it may assist in the depiction of breast cancer to place men and women side by side in the visual and oral storytelling outcomes for this project. This strategy was also suggested in a MBCC (2021) story by Cecil Herrin, where he states:

> All of the images out there about breast cancer should not be of women. Have a man standing side by side with a woman in the pictures. We need the exposure...

It is the creation of artworks in this research that may be shown publicly to raise the visual presence of male breast cancer, it is by including the participants in review of the artworks prior to exhibition that also allows them critical agency. It is an inclusive strategy of placing men and women with breast cancer, the known idiom, that connects the assumption that breast cancer is female with the actuality that it can affect anybody (Butz & Besio 2004, p. 354).

## 2.3. Summary

During my reflection on the theoretical underpinnings, I can understand that breast cancer in society has been gender stereotyped – in part this is due to the large numbers of women in comparison to men who are diagnosed with the disease (NBCF 2021). However, the Pink Ribbon Campaign (see Section 2.1), the marketing in pink, has also embedded the assumption that breast cancer belongs to women – which is not ideal for those other than women (BCNA 2021). Sections 2.2 including subsections 2.2.1, 2.2.3 and 2.2.4 explored the consequence for men with breast cancer, they are stigmatised (Halbach 2020) as a breast cancer diagnosis contests their sense of masculinity (J Boyes, 2021, pers. comm., 1 March). They may be marginalised and *othered* not only in representation (BCNA 2016), but also in health care situations (Halbach 2020). These issues amount to trauma for males, and their reluctance to "come out" with their experience is in part due to self-abjection, this in turn limits the visibility of men with the disease and sustains low awareness.

In Section 2.2.5, I explored strategies to counter the assumption that breast cancer is a female disease, to give visibility and voice to male patients. McRuer (2008), and Leys (2000) suggest that it is the "coming out" that allows for individual healing and acceptance of the diversity of bodies with breast cancer. Men, however, are reluctant to share their experience of breast cancer; so, my strategy is to collect Autoethnographical representations from the Male Breast Cancer Coalition website (MBCC, 2021) then collate these with two principal participants (who are male) and video of female participants from my Honours research (Baker, 2016). In this way, I appropriate idioms from the dominant culture and assimilate it with Autoethnographical representations to create inclusive creative outcomes (Butz & Besio 2004, p. 354). The methodology for how these Autoethnographical representations are analysed and articulated into artworks is described in Chapters Four and Five.

# **CHAPTER THREE: ARTIST REVIEW**

The purpose of this chapter (Chapter Three) is to review historical and contemporary artists that provide models for exposing, critiquing and subverting the dominant gender constructs and body ideals in society. The review of artists and their artworks will particularly discuss issues of marginalisation and exclusion pertaining to minority groups as well as offering strategies for both empowerment and inclusivity through the project's specific focus on male breast cancer survivors. This review interrogates how artists articulate disease, trauma and ultimately aims to address the limited examples (if any) of where male breast cancer are visually represented. It is through exploring the impact of how contemporary artists represent breast cancer that allows me as an artist-researcher to consider visual strategies which may be employed to raise awareness of male breast cancer. The importance of reviewing the diverse representational strategies of contemporary artists particularly lies in presenting alternative and critical modes of image-making and concept development which counteract the often "sanitised" misrepresentations of media campaigns (Klein 2018, p. 5). I have selected pivotal artists and connected their work in terms of their aesthetics and methods in terms of providing insights into the development of my own creative outcomes. As my artist review is extensive, the artists who were reviewed but not included in this exegesis (due to word-length or focus constraints) are mentioned in Appendix A.

Firstly, as my project explores the marginalisation of men in breast cancer awareness campaigns, my project does not intend to undermine feminist discourse in any way, but rather to engage directly with it in further exploring the way dominant power dynamics could be overturned. I explored French sculptor Louise Bourgeois (b. 1911), the German conceptual artist Rosemarie Trockel (b. 1952) and the French artist Annette Messager (b. 1943) to interrogate how they used their practice to critique societal norms by challenging entrenched modes of perception of gender. Following on from this, I reviewed American poet and activist Audrey Lorde (b. 1934), British photographer Jo Spence (b. 1934) and American photographer Matuschka's (Joanne Motichka b. 1954) photography to critique their Autoethnographical representations of breast cancer. Autoethnographic representations are self-representations of experience of breast cancer by survivors, in written and/or visual media; this is discussed in detail in Chapter Four (Section 4.4). Lorde, Spence and Matuschka would be considered *insiders* as they had been diagnosed and treated for the disease. Traditionally, breast cancer as an overarching health issue was considered as a taboo subject; by publicly sharing their artwork, Lorde, Spence and Matuschka have brought attention to the disease for women (Peterson & Matuschka 2004, p. 502).

In my review of contemporary artists, I have included in my investigation images of men with breast cancer. I begin by interrogating American photographer Hannah Wilke (b. 1940), American Photographer David Jay (b.1959) because he began including men in his *SCAR Project* (2011) after being approached by Dr Oliver Bolger, male breast cancer survivor and breast cancer researcher. Jay is an outsider having never experienced the disease but some of his images were published on the Male Breast Cancer Coalition (MBCC) website. From the MBCC website, I selected videos by Steve de Gardo, breast cancer survivor, (<https://www.youtube.com/watch?v=3CJ5VgtH-bU>) and Nicholas Sadler Barrelmaker Videos' documentary video of William Becker, now deceased breast cancer patient, (<https://timeslikethesefilm.org>) these videos are autoethnographical representations of male breast cancer; the intent is to interrogate how men wish to be

represented in visual discourse.

I reviewed the work of Australian sculptor Dan Elborne (b.1989) and Australian textile artist Haya Cohen (b. unknown) to see how they used their *outsider* perspective to represent breast cancer in metaphorical images. My position as an artist-researcher is unique in that I am both an *outsider* and *insider*. I had breast cancer and as such I am an *insider*, however, as being one of the dominant genders being represented by a female gender stereotyping of the disease, my experience may differ from a man's experience and as such, I am also an *outsider*. As an artist, I combine this *insider-outsider* researcher tension and see a sense of responsibility to make visible those who have been marginalised or omitted alongside my own journey and experiences of breast cancer. The explanation of the *insider* and *outsider* researcher positioning is further described in more detail in Chapter One, Section 1.2.

Finally, I explored the work of American installation artist Ann Hamilton (b. 1956) and American sculptor Janine Antoni (b. 1964). Hamilton is a

multidisciplinary artist like me; I wished to explore how she used her arts practice to approach sensitive subjects so that I may glean strategies to use in my own artworks. Antoni was reviewed as she aimed to create artworks that act as a *milagros*, a symbolic image used for healing. It is through the interrogation of artists' practices both historically and contemporary, that I intend to glean strategies to effectively articulate male breast cancer, to respond to the manifesto of my principal participants, and to raise awareness that the disease does exist in men (Fincher & Ritchie, 2017).

### 3.1. Artists who subvert societal norms

This section interrogates the notion of patriarchy and the ways in which artists, through their diverse practices, can challenge its efficacy as well as offer insights into dominant gender constructs and body ideals. I will review Bourgeois and Trockel as their approaches range from confrontational to subversive. Messager, like Trockel, is investigated as she used textiles as a modality to critique societal representations and attitudes towards minorities. Through investigation of these art practices, I intend to find strategies of subversion to engage in my own arts practice.

Bourgeois' artwork is of importance to this project as she uses replicated body parts, her art practice is often referred to as a cathartic form of the artist's engagement with her childhood trauma; particularly in terms of her relationship with her father (Sundberg 2010). Bourgeois' practice involved sculpting forms that replicated disembodied body parts and she either repeated the forms or blended them so that new forms and ideas would emerge (Rosenfeld 2012, p. 12). The use of replicated disembodied body parts in her sculptures was an intrinsic part of her practice; she used breast and phallus forms to confront subjects which were often regarded as taboo (Sanchez-Guzman 2012, pp. 158-159). For example, *Mamelles* (1991) (see fig. 3.1) includes a frieze and a row of breasts. By creating a composition of breasts in a frieze, an architectural form, she alludes to the structure of male dominance and entrenched patriarchy (Sanchez-Guzman 2012, p. 152).



Figure 3.1: Louise Bourgeois *Mamelles* 1991 Source: https://www.tate.org.uk/art/artworks/bourgeois-mamelles-t11916

In families with a patriarchal structure, like Bourgeois', the father is the authority figure (Sanchez-Guzman 2012, p. 158). In the installation work *Destruction of the Father* (1974) (see Figure 3.2), Bourgeois critiqued the norm of male domination in society; Bourgeois imagined the father figure was pulled apart and eaten in a form of cannibalism, which was fuelled by the artist's resentment (Schiller 2020, p. 381). As Schiller (2020, p. 382) further notes about Bourgeois' work: "In the center of this giant oral cavern, bathed in red light, is placed a long table where animal scraps, cast in plaster are scattered, leftovers of the cannibalistic repast".



Figure 3.2: Louise Bourgeois *The Destruction of the Father* (1974) Source: https://www.thelondonlist.com/culture/louise-bourgeois

Within this contextual reading, Bourgeois' *Destruction of the Father* (1974) (see Figure 4) challenges the norm of male dominance by simulating the murder of the father figure to signify killing off patriarchal society (Sanchez-Guzman 2012, p. 152). As a contrast to the father figure in *Destruction of the Father* (1974) were Bourgeois renowned breast costumes which were created by casting latex from a plaster mould, for the sculpture *Avenza* (1968-1969) (see Figure 3.3). Bourgeois used latex as it evoked the appearance of skin, she replicated the softness of the breast, the body part commonly associated with the feminine; she invited art critics to wear the breast costume during the performative part of her *Confrontation* (1978) installation to critique patriarchal society (Sanchez-Guzman 2012, p. 152). The breast costume elevated the feminine or mother figure into a position of power (Sanchez-Guzman 2012, p. 160).



Figure 3.3: Louise Bourgeois, pictured 1975, wearing her latex sculpture *Avenza* (1968–69), which became part of *Confrontation* (1978)

Source: https;//www.theguardian.com/lifeandstyle/2016/mar/14/louise-bourgeois-feminist-

art-sculptor-bilbao-guggenheim-women

Like Bourgeois, Trockel used the approach of appropriation of materials and processes as well as images from patriarchal society to critique gender imbalances. Trockel's art practice engaged a computer-controlled machine to create knitted paintings. In doing so, she developed a praxis which presents a contrast to hand knitting as a craft form (Stadel Museum 2021). She used her wool-based pictures as a counterpoint to the male dominated art scene at the time. In particular, her knitted paintings are her response to an art critic's comment that women could not create art. Hence, Trockel's knitted painting became an act of subversion to this patriarchal form of thinking (Doherty 2006, p. 722). It was by using a traditionally feminine craft, a devalued modality of knitting, and combining it with text and images that she could make a critique (Kraynak 2014, p. 161). In *Who Will Be In In '99* (1988) (see Figure 3.4), the title of the artwork references the rankings of artists which emerged in the 1980s. She appropriated the crucifix used in Kashmir's Malevich's *Supremist* paintings as a way of critiquing the male hierarchy of modern painting (Stadel Museum 2021).



Figure 3.4: Rosemarie Trockel, Who Will Be In In '99? (1988)

Source: https;//www.skarstedt.com/exhibitions/rosemarie-trockel2 Trockel's sense of ambiguity and open-ended approach in addressing gender constructs within her artworks enact as a disruptive agent (Kraynak, 2014). The knitting machine and its process, evokes both industry and the masculine, while the yarn usually associated with the stereotypical feminine craft was subversively used as the material Loughery (1992, p. 54). As Fenner (1994) explains "Trockel has symbolically sewn together the strands of prejudice, machismo and pseudo psychology that shape popular modes of perception and preconception" (p.19).

In *Untitled* (1985) (see Figure 3.5), the repetition and juxtaposition of woolmark logo and playboy bunny ears highlights the categories women were placed in: domestic or sexualised and objectified. In putting the two images side by side, she undermines established ideals of being feminine and critiques gender politics (Kraynak, 2014). It is the combination of art practice in knitting and symbolism in the images that forces the audience to consider a different perspective (Fenner, 1994).

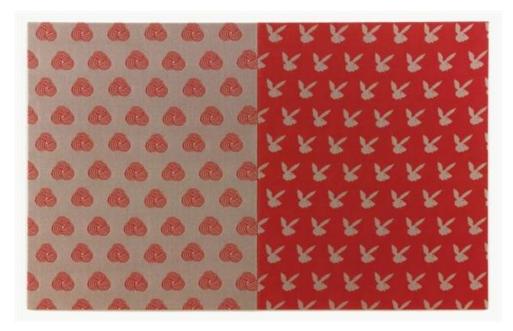


Figure 3.5: Rosemarie Trockel Untitled (1985)

Source: https;//www.coleccion.caixaforum.org/en/obra/-/obra/ACF0343/Untitled

Knitting has a history dating back at least 900 years; Schuiling (2014) suggests that knitting is a leisure activity and is rarely used as a conceptual medium for artists. Conversely, Orton-Johnson (2014, p. 307) explains that knitting is a subversive vehicle as a result. The once devalued activity of knitting was taken up by third wave feminists and transformed into an activist artform that had the power to critique

(Fields et al. 2014, pp. 151-152). Beveridge (2012, p. 10) also explains that textiles are a signifier of humanness, and some cultures believe that handmade clothing embodies the essence of a person. Knitting and other textile-based approaches are often used within the work of Messager to allow the viewer to identify with and consider the sense of humanness of her artwork, Messager made hybrid objects as her strategy was to be subversive rather than direct; she created artwork with dead animals, stuffed toy animals and fragments of photographs of women's bodies as an artistic comment about marginalisation and oppression in patriarchal society (Russell 1995, p. 2). For example, in *Boarders at Rest* (1971-71) (see Fig. 3.6) Messager knitted clothing for dead birds (Artner 1996, p. 13). Messager then displayed the clothed birds in vitrines to replicate museum cataloguing and the arrangement of the birds in rows appeared as if they were sleeping in a communal dormitory (Turney 2009, p. 122).

In *Boarders at Rest* (1971-72) Messager makes a subversive reference to the abject poverty pensioners lived in and, as they were elderly, their lives bordered upon death (Stiles & Selz 2012, p. 330). It is the juxtaposition of the bodies of birds and placing them in a different context that the viewer may understand the plight of the pensioners and may renegotiate their perspective (Fenner 1994). Most importantly, the very act of knitting cardigans for these dead birds, an action of care and nurture – a potentially feminine associated attribute – for those who are forgotten, marginalised or deceased (Artner 1996, p.13). The very knitting process within this work is an act of subversion.



Figure 3.6: Annette Messager *Boarders at Rest* (1972) Source: https://flashbak.com/dead-sparrows-in-hand-knitted-jumpers-1972-417560

# 3.2. Photography and feminist breast cancer artists

One modality that has exposed viewers to representations of experiences they may never encounter is photography (Johnson 2010, p. 70). Photography is also a modality which can shape or visually influence society. As Solomon-Godeau (2005, p. 104), American art critic, explains, photography has become "a principal agent and conduit of culture and ideology". This is collaborated by Susan Sontag, American filmmaker and political activist, who explained that photography has the ability to perpetuate or to challenge commonly held beliefs (cited in Jurich 2015, p. 11). This is particularly so, given photography often operates within or is affiliated with the documentary genre; where image-making is considered as "recording" human experiences (Solomon-Godeau 2005, p. xxvii). Interestingly, while documentary photography is perceived as providing evidence in its representation of accounts or events, it is too, a subjective form in its construction of narrative (Solomon-Godeau, 2005). That is, documentary photography still involves the photographer's process of selecting the subject matter, process of framing and cropping as well as many other subjective processes in constructing the photographic

image. Within this context, the imaging of breast cancer can critique commonly held beliefs which are perpetuated through commercial and media stereotypes (Bolaki 2001, p. 7). As Ehlers (2105 p. 333) explains, "A [second] key trope for/of breast cancer is captured in the "survivor figure" and its accompanying aesthetic of heroic femininity". These concepts are further explored by the photographic practices of artists such as Jo Spence (1982 – 1986) and Matuschka (1993). These artists aim to question medical treatments for women. Both artists broach a subject that is traditionally taboo – breast cancer – and in the process of photographing their naked torsos they raise awareness of breast cancer and address it in within a mainstream and accessible media context (Peterson & Matuschka, 2004).

The intention of exploring art practitioners who portray breast cancer was to see if their artwork impacted in any way on the awareness of the disease itself. Historically, breast cancer has been a taboo subject, but through the activism of the second wave feminist artists since the 1970s, breast cancer has entered the public domain (Peterson & Matuschka, 2004, p. 502). Audrey Lorde, author of *The Cancer Journals* (1980), wrote explicitly about her experience of breast cancer, the ravaging effects of surgery and treatment. Lorde also refused to wear a prosthesis after a mastectomy for breast cancer because she referred to the concealment of mastectomy as "silence and invisibility" (Bolaki 2001, p.1). Activism against the stigma of the disease also began to emerge with visual images, including photography, of women with breast cancer (Fernandez-Morales & Menendex-Menendez 2021, p. 11).

Feminist artists such as Jo Spence and Matuschka, however, made visible the effects of breast cancer and in doing so critiqued commonly held beliefs about the disease. For example, when it was common practice to surgically treat breast cancer patients with a mastectomy, Jo Spence gave the message that people should be included in decisions about surgical options (Rosenblum 1998, p. 152). In her photographic series *The Picture of Health* (1982-1986), (see Figure 3.7) Jo Spence photographed her diseased breast in a documentary style, with text referring to it as "her property" (Bolaki 2001, p. 6). By placing a question mark after the words "Property of Jo Spence ", written on her breast, she questions the "one size fits all" surgical procedure of mastectomy for breast cancer at that time (Rosenblum 1998, p. 152). The use of a question mark and text is a visual strategy; she argued that there

were alternatives to breast amputation (Dennet, Radley & Bell 2011, p. 234). As Spence (cited in Bolaki 2001, p. 5) herself explains, this image (See Figure 3.7) became "a talisman to remind myself that I still had some rights over my own body". Her desire was to convey her disapproval of the dominance of mastectomy over lumpectomy, to create images that advocated for alternative health and patients' rights (Dennet, Radley & Bell 2011; Rosenblum 1988).



Figure 3.7. Jo Spence and Terry Bennett *The Picture of Health 1982-86* (Spence 1982-86) Source: elephant.art/can-breasts-tell-us-contemporary-culture/

Feminists including feminist artists paved a way, leading to a greater awareness about the disease (Bolaki 2001, p. 3). American artist, Matuschka's Pulitzer Prizenominated photograph, *Beauty Out of Damage* (1993) (Figure 3.8) broke the topless female taboo; It was one of the first images in mainstream press that challenged "the absence of bodies with breast cancer in the visual field" (Ehlers 2015, p. 335). As Bolaki (2001, p. 7) explains, "the image invites the gaze and qualifies as an aesthetic nude". Matuschka's *Beauty Out of Damage* (1993) was on the cover of *The New York Times* in 1993, becoming an iconic symbol of breast cancer (Peterson & Matuschka 2004, p. 498). The image *Beauty Out of Damage* (1993) was also published in 2003 and 2011 in *LIFE* Magazine as one of "100 Photographs That Changed the World"; when the image was first featured *The New York Times* received a magazine record number of mail responses to the image (Peterson & Matuschka, 2004, p. 493). *Beauty Out of Damage* (1993) was created so that it was in a sense regarded as "beautiful", so that it was accepted within the mainstream (Peterson & Matuschka, 2004, p. 507), but it also contained a powerful message that "You Can't Look Away Anymore" – the headline to the image when it was published in the 2013, 20th Anniversary edition of *The New York Times* Magazine (Bolaki, 2001, p. 7) (See Figure 3.9).



Figure 3.8: Matuschka, *Beauty Out of Damage* (1993)

Source:

www.beautyoutofdamage.com/Aboutphoto



Figure 3.9: Matuschka, *Beauty Out of Damage* (1993)

Source:

www.nytimes.com/2018/08/15/insider/b reast-cancer-mastectomy-photo Matuschka's *Beauty Out of Damage* (1993) was published internationally in media and academic journals; the effect of the mass media release of her image has opened up dialogue about the disease in women (*Beauty Out of Damage*, 2021). As Fernandez-Morales and Menendez-Menendez (2021, p. 5) explain this was an "in your face" image which forced the viewer to recognise the impact of breast cancer surgery on the body; it was a "wake up call". *Beauty Out of Damage* (1993) became a catalyst for change, a shift in the paradigm around breast cancer (Peterson & Matuschka 2004, p. 502). As Matuschka explains:

Because of the extensive exposure my imagery received from national and international publications, advocacy organizations and activists requested the works for a variety of purposes. Many advocates used my images in their demonstrations, newsletters, actions, auctions and rallies. The breast cancer movement eventually became an internationally recognized 'company' with an agenda, support lines and actions/ demonstrations worldwide. I discovered that my success meant success for others as well: Other women who had had breast cancer began making imagery and getting their pictures out at the rallies as well. All of a sudden it was okay to put a face in a photograph that depicted a mastectomy, or a lumpectomy, or a view of a torso that had been reconstructed after breast cancer surgery. (Peterson & Matuschka, 2004, p. 502)

By the early 1990s, breast cancer research and charities became vocal and visual with the "coming out" of female protagonists (Peterson & Matuschka, 2004, p. 502); coupled with the growth of the Pink Ribbon Campaign breast cancer awareness has increased globally. As Pia Peterson from *The New York Times* explains:

The breast cancer awareness campaign has become a multibillion-dollar industry, and breast-conserving lumpectomy surgery and radiation therapy have become the preferred method of treatment for breast cancer, replacing mastectomy. (Peterson 2018, p. 2)

Considering the awareness paved by feminist artists, the next section discusses contemporary art practices and how artists have articulated breast cancer. Currently men are underrepresented, if at all, in the depiction of breast cancer (Donavon & Flynn 2007, p. 465); my aim is to therefore find male representations, if possible, so that I may induce how men may wish to be represented. Specifically, I have selected

artists who hold *insider* and *outsider* positionings in terms of breast cancer, interrogating their practices to glean strategies for possible inclusion into my own artworks.

# 3.3. The role of photographic and video representations of breast cancer in contemporary art

There are two perspectives emerging from my investigation regarding this artist practice review: one is that fine art photography employs a "documentary" style; which is an approach depicting nude breast cancer patients that may be confronting (Fernandez-Morales & Menendez-Menendez 2021, p. 4). The other is metaphorical representation which may require more reflective thought by the viewer; each modality may be absorbed differently; metaphor is discussed in this Chapter's Section 3.4. Photographs explicitly showing surgical scarring may be the "shock" effect needed to raise awareness that male breast cancer does exist. To place photography and video in context of the artists that I reviewed, I looked at the medium of photography, how it may be used as a conceptual underpinning and from both *insider* and *outsider* perspectives.

Photography is considered an invasive modality because it challenges our concept of reality by highlighting experiences we may never encounter (la Grange 2005, p. 125). The viewer internalises an image and thus a photograph is subjective but, also, the photographer/artist makes subjective choices too. For example, the framing of the photograph, selecting, editing and cropping of the photograph image (Solomon-Godeau, 2005, p. 87). Often the positioning of the photographer is also considered, for example, a male photographer documenting a female subject could enact a patriarchal gaze. The photographer may make choices that give illusions of the subject as being erotic, even pornographic (Solomon-Godeau 2005, p.220). As Szarkowski (cited in la Grange 2005, p. 16) explains, photographers have opportunities to show multiple perspectives of their subject, as a camera may capture many images from different points of view. So female photographers documenting their own bodies subvert the patriarchal gaze and thus can visually depict their own version of events, an Autoethnography, the photographer is an *insider* rather than a voyeur (la Grange 2005, p. 128). Conversely, a healthy body abled person who documents a disabled person, may by their positioning, cause an imbalance of

representation often whereby the subject is a spectacle or part of the notion of "enfreakment" (Richardson 2016, p. 177.).

In light of the discussed photographic discourse, the selection of artists in this section presents an important case in arguably producing non-sanitised representations of disease so that an emotional and conceptual "hook" and an intimate connection between viewer and subject may be created (Sontag cited in la Grange 2055, p. 126). For example, contemporary American feminist artist Hanna Wilke (1992), deals with her disease and her eventual death through a photographic lens. La Grange (2005, p. 125) explains that if the researcher is an *insider* documenting their experience the image is no longer deemed to be "victim" or a "objectified spectacle", photography as the power is in the hands of the artist. Wilke's earlier images were highly criticised during the feminist movement because artists withdrew from using sensuality and beauty of the female form, Wilke was attractive so her self-portraits attracted criticism (Zaytoun 2008, p. 138). The image of Intra Venus (1993) (see Figure 3.10), was an antithesis to Wilke's earlier practice, here she documents her own experience of lymphoma, an Autoethnography, the decaying and dying of her beauty due to the disease process, it triggers feelings or emotions in the viewer (Harrison cited in Andrews and Bamburg 2004, p. 117).



Figure 3.10: Hannah Wilke *Intra Venus* (1993) Source: https://muse.jhu.edu/article/25580

Photography provides the viewer with insight into private scenes that they may never have personally experienced. In *Intra Venus* 1993, it is by the use of the close-up, that the viewer gains a connection to the subject in the photograph; the close-up photographic image is a means of creating a sense of intimacy between photographer and subject as well as viewer and subject (la Grange 2005, p. 127). This intimacy between photographer and subject allows the viewer clarity and an emotional connection (la Grange 2005, p. 126). Once a connection has been established a viewer can assimilate the image and imagine themselves in the same predicament, whereby an empathy is created, perhaps a common understanding that we will all eventually die. *Intra Venus* (1993) also portrays Wilke's vulnerability through the use of a close-up, and the viewer of the works can internalise the image's personally confronting narrative (Tierney 1996, p. 44). Although an experience of disease may be foreign to the viewer, an empathy for Wilke is established and in doing so, it creates an emotional message (la Grange 2005, p. 125).

While David Jay's SCAR Project (2011) can be considered as having an outsider perspective as he had not experienced breast cancer (la Grange 2005, p.127), he shows an empathy for his subjects as his SCAR Project (2011) was originally inspired by a young female friend who had breast cancer. He photographed women between the ages of 18 and 35, to raise awareness of young women with breast cancer (Young Survival Coalition 2005-2016). This cohort generally has a high mortality rate due to the aggressiveness of the disease in younger patients (Whiteside, E 2017, pers. comm, 17 November). Although Jay (2011) had not experienced breast cancer, there is an intimate relationship implied between the photographer and subject (la Grange 2005, p. 127). All of Jay's subjects volunteered to be photographed; he had a deep involvement and commitment to record the scarring of breast cancer (Ehlers 2015). All of the subjects were photographed with naked torsos, they were, like Wilke's Intra Venus 1993, close ups, to create an intimacy between the photographer and his subjects. Jay presented his images to the National Breast Cancer Foundation in 2012 and through the exhibition of his photographs and lobbying from younger women at the 2013 Community Conversations, issues relating to young women have been included in projected research in Australia (NBCF 2017-2018).

In 2013, Jay was approached by Oliver Bolger, cancer researcher and breast cancer patient, to include male patients in his *SCAR Project* (cited in MBCC 2021). Bolger became one of a few men to be photographed by Jay (Jay 2013) (See Figure 3.11). Jay's images have been used in conjunction with written stories on the MBCC (2021) website. The viewer cannot ignore what they have witnessed: men with mastectomy scars. The viewer can then gain a further interpretation of the image by connecting the didactics to internalise the experience of men with breast cancer, to create a subjective connection or emotional hook (Harrison cited in Andrews & Bamburg 2004, p. 118). It is through this emotional agency that the viewer may internalise an image of a male body with breast cancer.



Figure 3.11: David Jay *Oliver Bogler*, *The Scar Project* (2013) Source: www.malebreastcancercoalition.org

Looking at naked male torsos also evokes an empathy for men with breast cancer, it is the viewing of men that also challenges the notion that breast cancer is only for women (J Boyages, 2021, pers. comm., 1 March). As the physical scars leave a visual reminder that men too can have breast cancer, this evidences that Jay has approached his male subjects with the same sensitivity as the younger women (Jay, 2011). Jay has since photographed many people with scars, with the aim to create acceptance of *all* different bodies.



Figure 3.12: Steve Gardo *Protect the Pecs* Video Still (2014) Source: https://www. youtube.com/watch?v=3CJ5VgtH-bU

As previously mentioned in Chapter One, during my Honours research in 2015-2016, I discovered the Male Breast Cancer Coalition website, at the time there was a handful of stories on the website. Now, in 2021, there are well over 150 stories and memorials. This increase of stories added a weight of knowledge to my investigation. On the MBCC website I found videos created by male patients, these videos reflect how men wish to be represented and their intention is to raise awareness of male breast cancer. For example, in Steve Del Gardo's male breast cancer patient, Protect the Pecs (2014) video (https:// www.youtube.com/watch?v=3CJ5VgtH-bU) he expresses stoicism and refers to his experience of breast cancer "as saving the pec" (Figure 3.12). While Nicholas Sadler Barrelmaker Films video *Times Like These* (2014) (<https://timeslikethesefilm.org>) (Figure 3.13) demonstrates the trauma for men by showing footage of William Becker in hospital as he describes the effects of his treatment. Both are Autoethnographical representations, by definition, these video artworks are reflections on their personal experiences of breast cancer (Robson & Sumara, 2016, p. 617). Gardo's Protect the Pecs (2014), refers to his fight, coupled with images of

him in a gym and boxing footage, he tells the audience that he will be "in their corner", supporting other men diagnosed with breast cancer. This video adds weight to an argument that no matter how masculine there is still a chance that breast cancer can be diagnosed in a male (Donavon & Flynn 2007, p. 466).

*Times Like These* (2014) (<https://timeslikethesefilm.org>) (Figure 3.13) follows the treatment of William Becker until his death from metastatic breast cancer on 17 September 2014. Among the images of medical treatment are close ups of William as he tells the viewer how he feels during his treatment. I found the video heart breaking and found it impossible to be unaffected by what I had witnessed. In 2013 I attended the NBCF Speakers Bureau training, at this seminar, the facilitator emphasised that presentations should provide an emotional hook so that viewers are invested in the fundraising event and thus will donate to the charity (NBCF Speakers Bureau, 2013). These videos were made by male breast cancer survivors and show efficacy in that they promote, to an extent, an authentic male experience. It was the footage of Steve Del Gardo sitting with his double mastectomy scars talking about how to help other men; these artworks provided an oral and visual emotional message; the focus is on the trauma of treatment evoking empathy in the viewer (la Grange 2005, p. 125).



*Figure 3.13: Nicholas Sadler, Barrelmaker Films Times Like These Video Still (2014)* Source: https://www.youtube.com/channel/UCvTGPMIeu8KrIUhDaBr5YKg

The strategies that I have gleaned from photographic representation of breast cancer is that an *outsider* position is best when there is an implied intimacy between subject and photographer (la Grange 2005, p. 127). It is the use of a close-up which creates this intimacy (Tierney 1996, p. 44) while auditory and/or didactics can add to the emotional connection with the viewer (NBCF Speakers Bureau, 2013). The strategies gleaned from this section are based on how men would like to be represented and have been embraced in my creative outcomes; this is discussed in detail in Chapter Five.

# 3.4. Metaphorical images depicting breast cancer

In contrast to the photographic work of Wilke (1993), Jay (2011), Del Gardo (2014) and Nicholas Sadler Barrelmaker Films (2014), metaphorical images contain symbolic objects. Ritchie (2013 p. i) explains that a metaphor is found in language and usually one idea or thing is explained in terms of another. Australian artists Dan Elborne and Haya Cohen have used sculptures as metaphors; their sculptures represent the ravaging effects of chemotherapy.

Elborne's One Drop of Blood (2013) (see Figure 3.14) is a sculptural work consisting of white ceramic shapes representing the number of white blood cells in one drop of blood. In this way, the artist uses quantitative and qualitative forms of data that are related to the process of chemotherapy. Elborne's installation is designed with audience engagement in mind and is a participatory work. As the audience remove the individual ceramic forms, this signifies the loss of white blood cells during chemotherapy and alludes to the ailing Elborne's mother experienced during her treatment (<https://.danelborne.studio/onedropofblood/>). The inspiration for One Drop of Blood (2013), was taken from the concept of erasure, the taking away of the ceramic shapes replicates the work of Felix Gonzalez-Torres' Untitled (Portrait of Ross in L.A., 1991) (<https://.danelborne.studio/onedropofblood/>). The significance was that these ceramic shapes were a reminder of his mother's experience of breast cancer. His memories are ghosted in the work and the taking away of the ceramic shapes represented the loss of his mother's strength during treatment. The facts, the actual numbers in One Drop of Blood (2013) give a genuine representation of the process of chemotherapy and the taking away of some shapes represents the ravaging effects of chemotherapy on the body, the symbolic shapes

enabled a physical manifestation of the depletion of strength for the viewer (<https://.danelborne.studio/onedropofblood/>). Elborne uses symbolic elements, ceramic shapes which are removed, to represent the *erasure* of his mother's health. While the artist Haya Cohen (2015) uses artefacts, such as the hair from a breast cancer patient, to also represent the concept of loss resulting from chemotherapy.



Figure 3.14: Dan Elborne, *One Drop of Blood* (2013) Source: https://danelborne.studio/onedropofblood/

During my Honours study (2015-2016), Haya Cohen, textile artist, became my mentor and I met her to discuss her practice. It was during my initial meeting that she told me about *Alchemy* (2011) and how she incorporated the hair of Patricia Wise, breast cancer survivor, into her artwork (Cohen (2015, pers. comm., 5 May). In *Alchemy* (2011) she wove the hair of Patricia Wise with strands of gold, silver, and copper, these metals are found in chemotherapy drugs (Cohen 2013). Cohen's *Alchemy* (2011) ghosts Patricia Wise's story of breast cancer treatment in the artwork (H Cohen 2015, pers. comm., 5 May). Wise's identity was embedded in her long hair, she was well known for it as it reached to her bottom (P Wise 2016, pers. comm., 14 October). As the precious metals in *Alchemy* (2011) were woven with the

hair, they gradually became less precious, an antithesis of alchemy: something precious – the beauty of Wise's hair – was transformed into something non-precious (H Cohen 2015, pers. comm., 5 May). I was fortunate to also meet Patricia Wise (2016, pers. comm., 14 October), breast cancer survivor, as she assessed my Honours thesis (2015- 2016). She explained how chemotherapy for her breast cancer treatment left her with long-term health issues. By weaving Wise's hair which she lost because of chemotherapy, it implied her health and emotional wellbeing deteriorated over the process of breast cancer treatment. The transformation of loss is manifested, the hair of Pat Wise intertwined with the metals, evoke *erasure* – the destruction of Wise's health and looks (H Cohen 2015, pers. comm., 5 May).



Figure 3.15: Haya Cohen *Alchemy* (2011) Hair, Silver, Gold, Metal Source: www. hayahagitcohen.blogspot.com.au

*One Drop of Blood* (2013) was a physical manifestation of the loss Elborne's mother experienced during chemotherapy. When viewed in relation to Cohen's *Alchemy* (2011), they give factual representations of the disease and the trauma of loss due to treatment. Both Cohen (2015, pers. comm., 5 May) and Elborne (<https://danelborne.studio/onedropofblood/>) have used the concept of *erasure* and amalgamated it with scientific research and facts. Both artists have ghosted the stories within their images to create an unsanitised recount of breast cancer experience.

#### 3.4.1. Installation art depicting sensitive subjects

As a multidisciplinary artist, it is also important to explore installations by artists whose themes may not always specifically relate to breast cancer, but they broach sensitive subjects through creating experiential, multimodal and immersive environments. For example, the American installation artist, Ann Hamilton's artwork is typically inspired by a specific site, but it is Palimpsest (1989) and CHORUS (2018) where she manifests visual representations of sensitive subjects such as deteriorating mental health and tragedy. I have therefore selected these two installations and refer to the textile performance in her artwork, a round (1993), to interrogate the use of materials and processes which may be applied in my own creative outcomes. Catherine Domor (2008, p. 243) describes a palimpsest as a scroll or book that had been written over, it is a writing surface that has been used again. It is the process of writing over that can also connote a different meaning and allow a viewer to consider alternative meanings. Hamilton considers that text is a material for artwork, rather than something to be read as its only approach of conveying meaning. From this perspective, text is used to create a deeper understanding (Hamilton cited in Wallach 2008, p. 54). Hamilton collaborated with artist Kathryn Clark to create *Palimpsest* (1989) (see Figure 3.16), in this installation they use excerpts from literature and pieces of newsprint which were covered in bees wax and laid as tiles on the floor or pinned to the walls of the structure to replicate a home (Johnson 2020, p. 2). The inspiration for this installation came from an elderly man that Hamilton knew who pinned notes over his walls in his home so that he could remember things (Johnson 2020, p. 3).



Figure 3.16: Ann Hamilton and Kathryn Clark, *Palimpsest* (1989) Source: <https://hirshhorn.si.edu>

Pamela Johnson (2020, p. 2) refers to a palimpsest as something that has multiple layers of meaning; it is the juxtaposition of the other elements in Hamilton and Clark's *Palimpsest* (1989) (see Figure 3.16) that create different meanings, thus allowing the viewer to reposition their viewpoint. For example, in the multiple medium installation *Palimpsest* (1989), it is the positioning of two cabbages being eaten by snails in a structure that appears to be made from text, excerpts and news clippings, that allude to the deteriorating mental health of the elderly man that Hamilton knew (Johnson 2020, p. 2). A palimpsest then, has different descriptions, a writing over of text to replace, or multiple layers of meaning; Hamilton and Clark's *Palimpsest* (1989) created a juxtaposition of elements in the installation.

The concept of juxtaposition is also exemplified in Hamilton's *a round* (1993) where she creates a large skein of yarn and knits it into a form during a performance artwork (see Figure 3.17). An oversized skein was created by winding yarn around pillars of the building so the yarn was entwined with the architecture. It is her performance art as an element in the installation around 1993 which interests me, she

sits facing the skein and unwinds the yarn and knits and knits and knits. Hamilton uses the repetition of knitting in her installations as a form of theatre, it is ritualistic (Lunberry 2004, p. 122). Knitting relies on the repetitive motion of making knots in yarn with the use of needles, it is a tactile and deeply embodied experience (Orton-Johnson 2014, p. 316).



Figure 3.17: Ann Hamilton, *a round* (1993) Source: https://www.annhamiltonstudio.com

Hamilton saw words as not only conveying meaning, but as a material to be used in artwork (Hamilton cited in Wallach 2008, p. 54). More specifically, *CHORUS* (2018) (see Figure 3.18) was installed in the subway station at the World Trade Center in New York, where text protruded from the wall as three-dimensional sculptures (Hamilton 2018). The words according to their size and position give importance within an artwork (Curnow 2016, p. 210). In Hamilton's *CHORUS* (2018) larger text was assigned to the title of "World Trade Center [sic]" in this way, the viewer's gaze is focused on these words; they become the most significant words within the dialogue (Hamilton & McHale, 2020, p. 226). Hamilton arranged the words in the subway leading to the site of the Twin Tower Memorial, on the Southern Platform words like "FOUNDATION," "FREEDOM" and "PROTECTION" were repeated – these words are from the 1776 United States Declaration of Independence. On the northern platform near the entry EVERYONE is repeated, while words from the 1948 United Nations Universal Declaration of Human Rights are present on both platforms (Hamilton 2018). However, it is the larger text differentiated in black as adverse to the white lettering that surrounds it that gives the title "World Trade Center" its sense of monumentality (Curnow 2016, p. 210). The repetition of words in the walls leading to the World Trade Center are in a Trajan typographic style, it references the ruler who was not only a soldier but a philanthropist and advocate for social welfare (Hamilton 2018). It was by using verbatim text from significant historical documents, by using typography that alludes to social welfare, that elevate the words in *CHORUS* (2018) to a memorial (refer Figure 3.18). Hamilton (2018) explains: "Recognitions are made and ideas are formed in and with words. The names of people and events are carved into stone and remembered" (p. 1).

The repetition of the words in *CHORUS* (2018) were selected to remember how America was founded, they act as a reminder that societal tenets remain despite tragedy, in this way *CHORUS* (2018) provides a visual discourse, a potential healing after the Twin Towers tragedy (Hamilton & McHale 2020, p. 228; Hamilton 2018).



Figure 3.18: Ann Hamilton, *CHORUS* (2018) Source: <www.annhamiltonstudio.com/public/chorus.htm>

#### 3.4.2. Healing motifs

Healing through artwork can be attained by the physical artmaking process itself. For example, in Bourgeois' artwork it was a personal cathartic experience that was manifested as an outward expression; a violent objection to patriarchal dominance (Sanchez-Guzman 2012, p. 152). Whereas American artist Janine Antoni was inspired by the concept of a *milagros*, an image of a body part which is placed in a church and the inflicted body part prayed for so that healing may occur (Panicelli, 2015, p. 385). The word *milagros* means miracles, and as Antoni explains, where milagros are hung there is the connection to the spiritual or supernatural (<https:// news.artnet.com/art-world/janine-antoni-1476760>). Antoni used this concept in her sculptural work where body parts are fused together to create new forms. In doing so, she explores the meaning of impossible juxtapositions. To compose (2015) (see Figure 3.19), is a woman's leg crossing over a leg skeleton; by placing them together she suggests the sexuality of the body part and the ultimate death of it. By placing sex and death together, she alludes to the spirituality of the *milagros*, the life and death of a body, the wish for healing of the ailing body and in turn ailing sexuality (Panicelli 2015, p. 385).



Figure 3.19: Janine Antoni, *To Compose* (2015) Source: www.janineantoni.net

The relevance of Antoni's *Milagros* (2015) is the hope that the work I make will allow healing from the individual experience (particularly in terms of breast

cancer) to the collective (Robson & Sumara 2016, p. 636). It is through facilitating retelling for the male breast cancer patients that I provide a platform for them to "come out" with their experience. As Sheikh (2008, p. 85) found, self-disclosure through talking about experience assists in the cognitive processing of trauma. Although I use published stories from the MBCC website, it is a "safe haven" for men to retell their experience; it is in their coming out with their experience, their stories ghosted in my creative outcomes that may allow for some healing. The review of artists created pivotal inspiration for my creative outcomes as it gave a basis to the artistic concepts which could also be embraced as subversive strategies. The materials and processes that I could incorporate into my artwork are justified in terms of this artist review.

# 3.5. Summary

From my review of artist practices, I have induced strategies in critiquing and visually subverting dominant gender constructs and body ideals that I can include within my own creative outcomes. As Richardson (2016, p. 3) explains, visibility is pivotal in raising awareness. It was by reviewing visual artists that I could identify strategies to disrupt the current awareness paradigm and provide alternatives in visual and oral storytelling. Louise Bourgeois challenged patriarchy (the dominant gender construct) by creating artwork that replicated disembodied body parts; but it was the breast costumes worn by art critics that acted as a subversive strategy, to undermine patriarchy and elevate the feminine (Sanchez-Guzman 2012, p. 160). Trockel's knitted paintings appropriated idioms from the dominant culture of patriarchy and highlighted the stereotypes assigned to women (Fenner 1994). Combining appropriated images with the process of a knitting machine (the masculine with the feminine) she critiqued the dominance of patriarchy and her approach acts as a disruptive agent (Kraynak 2014). Bourgeois' and Trockel's artist strategies may be implemented in my own artworks, the pivotal strategies are: to give visibility to the marginalised cohort (male breast cancer patients), appropriate idioms and images from the dominant culture (female engendered stereotype) by using a combination of these it may act as a disruptive agent to subvert the assumption that the disease only exists in women, Material choices and processes may also critique cultural assumptions by visually elevating the minority and can also emote

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humanness (Beveridge 2012, p. 10), for example, the process of handknitting in Messager's *Boarders at rest* (1972) alludes to an empathy for the subjects of the artworks (Artner 1996, p. 13).

Feminist photographers such as Spence and Matuschka turned the patriarchal gaze around by photographing themselves in the nude, and thus created Autoethnographical representations of breast cancer. Both artists broke the topless breast cancer taboo and in doing so critiqued the medical treatment of the time and advocated for patient's choices in treatment (Bolaki 2001). An image of a person with breast cancer has the potential to cause dynamic shifts in public perception; for example, Matuschka's image has been published globally and has created awareness and de-stigmatisation of the disease for women (Peterson & Matuschka 2004, p. 502). Photography enables people to "see" events and human encounters they may not have personally experienced or been exposed to (la Grange 2005, p. 127). In my research this premise has been explored through a variety of modalities where the photograph, video or ultrasound is presented in other media such as paintings, drawings and posters. It is the positioning of the image-maker that has the power to "enfreak" or empathise with the subject (Richardson 2016, p. 5).

Factual quantitative data representation such as statistics of breast cancer patients in Australia assimilated into metaphorical artworks provide a powerful recount of the devastation of the disease. This also includes where textural discourse is manifested in representational text. For example, the exact number of cells in Dan Elborne's *One Drop of Blood* (2013) assists the viewer to conceptualise the gravity of loss when some of the ceramic forms are taken from the installation. The interactive process of his artwork is based on facilitating audiences to engage with factual knowledge as well as the breast cancer experience (www.danelborne.studio/onedropofblood/). While authentic artefacts such as hair from patients, photographs and video or people's experience of breast cancer are used in artworks they add authenticity to the creative outcomes (Cohen, 2013; MBCC, 2021).

Text can be an artwork; it can also be its own genre and can include taking on its own "materiality" as an artform. The power of text is in the choice of words that are used (Hamilton 2018). Verbatim text, in Hamilton's *CHORUS* (2018), reference pivotal words from the 1776 United States Declaration of Independence and the 1948 United Nations Universal Declaration of Human Rights to remind the viewer that the tenants of society remain intact even after tragedy. It is in the repetition and the monumentality of the words that creates a memorial and potential healing (Hamilton, 2018).

Sculptural forms may resemble disembodied parts, but they can also act as *milagros* and have the potential to create healing from the individual to the collective (Robson & Sumara 2016, p. 617). I aim to create artworks that may impart a deep understanding and empathy for the people with breast cancer. It is through the intention of this research that the artworks will act as a *milagros*, a form of healing from the individual to the collective. The correlation of the artist review, theoretical underpinnings and methodological approaches embraced in my creative outcomes are elaborated in the Findings Chapter of this exegesis (refer Chapter Five).

The following chapter (Chapter Four) explores the methodological approach of Autoethnography and how I use it in combination with Grounded Theory coding. As men are reluctant to share their experience of breast cancer, due to social stigma, I included videos of two principal participants and written stories from the Male Breast Cancer Coalition (2021) website to create a data set of 167 male stories of breast cancer. Currently male breast cancer is under-researched so it was pivotal that I engaged in a methodological approach that would provide a rigorous analysis and also allow for male breast cancer stories to be told.

# **CHAPTER FOUR: METHODOLOGY**

## 4.1. Introduction

Working within a predominately qualitative research paradigm (Hammersley 2013), the aim of this chapter is to address the key research methodologies, methods and processes engaged within this practice-led study. This chapter will also identify, contextualise and discuss my creative approaches and artistic choices of materials and processes through my engagement with and making of original artworks. My practice-led study predominately engages with Autoethnography (Ellis, Adams & Bochner 2010) and Grounded Theory (Charmaz 2008) as key research methodologies within this project. I draw on Butz and Besio's (2009, p. 1667) description of Autoethnography who define it as a reflexive practice where the researcher ponders on experiences similar to their own. I draw on this definition to describe the lived experiences of men with breast cancer through my art practice. This is done from an *insider* as well as an *outsider* position (Ellis, Adams & Bochner 2010) as on one hand I have encountered breast cancer in my own life, yet this personal experience lies outside of a male perspective. In this way, I see my practice as a catalyst for providing a public platform that provides some agency for male breast cancer patients. That is, my artworks are all anchored in representations by male breast cancer patients who have shared their stories, either with me or in public fora. These are analysed below, using the coding methods influenced by the emergent production of knowledge (through practice) contained in Grounded Theory, which, as described by Kathryn Charmaz (2008) is a systematic and inductive approach to collecting and analysing data; there are no preconceived ideas and no hypotheses. The purpose of Grounded Theory is to create new knowledge from the collected data and it is particularly suitable for research where little is known about the subject (Charmaz 2008). I deploy the coding practice of Charmaz (2008) as it is an emerging process of analysing data, my approach is to establish theoretical categories, then evidence is collated to support each category and these are articulated into artworks.

I situate myself, the researcher, as an informed practitioner who has experienced my own breast cancer diagnosis and treatment. My creative outcome is therefore the manifestation of my exploration of different representations of male breast cancer and the individual stories of male breast cancer participants within my project. My visual works are, but not limited to: video, watercolour painting, textile installations, printing plates, illumination drawings, artist journals, coding journal as well as conference presentations. The use of diverse materials and performative artworks reflect the tactility and embodiment of the disease, which has a physical manifestation on the bodies of breast cancer patients. This chapter outlines the key methodological applications, and how these align with several data gathering methods, over the time allocated to this doctoral study.

This research process is divided into three district phases: pre-confirmation, post-confirmation (including exegesis and final creative outcomes), and exhibition for final submission and publication with Breast Cancer agencies such as BCNA. Each phase is planned and scheduled towards my completion date. The data collection methods and analysis are articulated in terms of my selected methodologies that comprise a combination of Autoethnography (Butz & Besio 2004) and Grounded Theory (Charmaz 2008). The rationale for using these specific methodologies is justified in terms of how my practice emerged from my interrogation of a primary, web-based resource (Male Breast Cancer Coalition 2021) where men share their breast cancer stories, and interviews with two male survivors. The methods for data collection are described and rationalised in terms of how they emerged from my process of making in alignment with the premises of Autoethnography and Grounded Theory as the broader methodological framework (Charmaz 2008). The analysis of data sets is outlined below in Section 4.5 and Table 4.1, and examples of my emerging work is also provided in Section 4.5.1 so that a rigorous and consistent approach is articulated over the phases of the research. Finally, the planning for my creative outcomes for public exhibition and conference presentations are documented to resolve the creative works (See Table 4.2). The knowledge that emerges from this practice is covered in more detail in the findings provided in Chapter Five of this exegesis.

My practice involves the collection and analysis of stories and articulation of findings in discursive and presentational texts for exhibition. I use Autoethnography as described by Butz and Besio (2004, p. 353), where research subjects represent themselves on their terms, to engage with the researcher. Autoethnography

accommodates for the collection of a wide variety of data (Ellis, Adams & Bochner 2010, p. 276), the underlying strategy is to collect and analyse Auto/ethnographical representations of men with breast cancer. As Butz and Besio (2004) explain, the role of the researcher is to pay attention to, respect and celebrate all self-representations and the researcher must make their own position, experiences and involvement explicit. The specific data sets in this research include written stories by male breast cancer patients; documentation in video of participants' stories; photographs of patients; artefacts inspired in response to interactions with participants; artworks created from analysis of collected data sets; readings from medical journals and facts from breast cancer agencies related to male breast cancer. These data sets are analysed using Grounded Theory coding as outlined by Charmaz (2008) to uncover common themes or actions; the frequency of common concerns men expressed specifically in their written stories, are documented in the emerging creative works that I especially designed and applied to visually render and represent my analysis. The new knowledge gained from this data collection, analysis and reified artworks is therefore derived explicitly from my artistic practice, and may be articulated into journal articles, conference papers or further discursive texts for exhibition beyond and outside the scope of this project.

# 4.2. Methodological aims and researcher positioning

The aim of my research is two-fold, to simultaneously create discursive and presentational texts (Abbs 1989, p. 32) about male breast cancer to raise awareness of the disease and to create a methodological model using my arts practice. My own art practice draws on Autoethnography and Grounded Theory as methodological approaches that consider the difficulties of men sharing their experience and in turn, relies on interviews with the men included in the Breast Cancer Network Australia Summit in 2017. In addition, I have liaised with an international male breast cancer support network to facilitate a large cohort of participants: the Male Breast Cancer Coalition begun by Bret Miller, American breast cancer survivor, founded in 2015 (MBCC, 2021). The rationale for the formation of the Coalition is underpinned by men generally being reluctant to share their experience and the MBCC (2021) website was an extensive source of data for this cohort that has otherwise been unsupported (R Ritchie 2019, pers. comm., 27 November).

My research aims to create artworks advocating for inclusive narratives of breast cancer. It responds to the absence of male breast cancer in the current public awareness paradigm (National Breast Cancer Foundation, 2021; E Whiteside 2017, pers. comm., 17 November). Employing a variety of oral and visual modalities is an important approach as it enables me to transfer and apply the findings in a tactile or tangible, and visible manner through my arts practice. My two principal participants, Rob Fincher and Rod Ritchie (see Section 4.6.1) are pivotal in my understanding of the struggle that male breast cancer patients face and they became the catalyst for this research. It is through sharing their stories that I hope to open up an inclusive dialogue about breast cancer. The Male Breast Cancer Coalition (MBCC) website (2021) is a publicly available interface designed to encourage male breast cancer patients to feel supported so that they are willing to share their experience. It provides a 'haven' for people with the disease to feel safe to share their experiences on their own terms (Betz & Besio 2004, p. 353). The rationale for using a published website as a source of male breast cancer stories is in response to the overall reluctance of men to share their experience, due to the body shame of being associated with what is stereotypically a "woman's disease" (Donovan & Flynn 2007, p. 464). My aim is, by sharing the insights gained from my research, the approaches and visual practice outcomes may be useful for future researchers of other diseases.

This research extends upon the study entitled *Acting in verbatim theatre: An Australian case study* by Dr Sarah Peter, a lecturer in theatre studies from Flinders University in Adelaide. Peter's (2016) research developed a participation model where she interviewed participants with alopecia, to research the female experience of hair loss (Peters 2016, p. 144). Peters, as a sufferer of alopecia, collected stories from other female alopecia patients in order to create a scripted play. Peters (2016) used verbatim text from her interviews to form some of the dialogue in the play. The similarities are that my participation in the research relies on my own common experience of breast cancer to encourage ways for male breast cancer patients to relate to their experience. Although the male experience may have unique issues that differ from my own, I see my methodological approach as a catalyst in providing a platform for these experiences/stories to be seen/heard and contextualised. Similarly, to Peters (2016), I use verbatim text; the difference is that I employ visual storytelling to articulate the verbatim component of my artworks. Like Peters (2016), I have a shared experience with my research subjects and as such am an *insider*. However, being female, my experience may have been different to that of a male, so in this context, I am an *outsider*. It is through a common experience of breast cancer with my participants in this research that my research bridges the gap between *insider* and *outsider* (la Grange 2005, p. 126).

#### 4.2.1. Ethical review

As this research involved interactions with male patients, I was required to make an application for Ethical Clearance. I applied through the University of Southern Queensland (USQ) and my Ethical Review H19REA060 (v2) – Ethics Application Approval was originally granted on 29 April 2019. The approval allowed for close-up video and audio of male and female participants (face shots only) as well as naked torso photographs of men. I added further amendments to allow pre-study video and photography to include a female naked torso and ultrasounds from one of my male participants. Participants in the research were video recorded and their experience of breast cancer was transcribed (see Appendix B1-4). The video transcripts were analysed to find the patterns of key issues relating to experiences of breast cancer.

My research allows for anonymity of participants and their participation was voluntary. however, Rob Fincher and Rod Ritchie consented to participate allowing their stories to be shared, and for them to be named, in my doctoral project. Rod Ritchie consented in accordance with University of Southern Queensland's human ethics guidelines and the conditions are outlined in the approved application. Unfortunately, Rob Fincher passed away during my doctoral research on 19 June 2019, but the Ethical Review committee confirmed that the prior consent during my Honours research (2015-2016) from Griffith University would be acceptable. These two men are my principal participants (see Section 4.6.1) where their images, use of their names and video recordings are used inside my creative works. To create a comprehensive picture of the male breast cancer experience, I used the MBCC website to collect a large cohort, the stories from these male breast cancer patients had an indelible impact on my emerging artwork.

## 4.3. An overview of methodological approaches

My research predominately engages within the qualitative research paradigm (Hammersley 2013) with some quantitative data collection on male breast cancer (NBCF 2021; BCNA 2021). My overall study is practice-led and relies on the creation of new knowledge through the making of artworks (Sullivan 2009; Hawkins & Wilson 2017). The Arts and Humanities Research Board (cited in Sullivan 2009, p. 47) describe practice-led research as an investigation through creativity and practice which may not be text-based, but rather in other arts modalities. Stemming from a question or problem, the researcher uses methods, contexts and outcomes in creative practice (Sullivan 2009, p.47). The very act of artmaking leads to new discoveries in both process and outcome (Sullivan 2009, p. 48). As male breast cancer is under-researched, it relies heavily on knowledge from female studies of the disease (NBCF, 2021). I assert that males are invisible in the portrayal and treatment of breast cancer, which is leading to a lack of public awareness and, in turn, lower survival rates for this cohort (E Whiteside 2017 pers. comm., 17 November; Cancer Australia, 2021). In making creative responses about the lived experiences of men with breast cancer, I include male breast cancer stories within the broader national dialogue about breast cancer. In turn, my engagement in a practice-led research study is about creating a space that provides visibility to these marginalised voices through the works I produce and publicly exhibit. Exhibiting works depicting a 'diversity of bodies' with breast cancer (McRuer 2006) serves as a key visual strategy in encouraging the viewer of the artworks to renegotiate their own understanding of the disease. It is also about bringing both medical and visual art communities together as well as engaging audiences within and beyond these fields.

In this research, I deploy and combine Autoethnography (Butz & Besio, 2009) and Grounded Theory (Charmaz, 2008) methodologies together to interrogate my central project's premise. Autoethnography within this research project will involve both written and creative responses to describe personal experiences to understand a cultural group. The aim of these methodological approaches is to 'authentically' speak against dominant stereotypes, and to articulate knowledge about this cohort in artwork, so that the creative outcomes may be shared in exhibitions and on public fora (Adams, Hollman & Ellis, 2014). Autoethnography further allows for the representation of male breast cancer patients to be included in the depiction of the

disease by using written or recorded stories of their experience (Ellis, Adams & Bochner 2010, p. 277). I am a participant and observer in this field, because I am a breast cancer survivor and, as such, I am part of a female breast cancer alumni. I use Grounded Theory as it addresses fields of knowledge and practice that are emerging. That is, Grounded Theory is a methodology where I can make creative work from my interrogation of the male stories. I recorded their experiences of being underrepresented through the ongoing coding process (Charmaz 2008, p.155). The absence of male breast cancer research is confirmed by the National Breast Cancer Foundation, which admits breast cancer research is based primarily on female studies (NBCF 2021). My research data is also analysed using Grounded Theory to find recurring themes in my own and the Autoethnographical representations by male breast cancer patients (Charmaz 2008, p. 163).

Although there are several key strategies in Grounded Theory, I engage in the inductive coding process where theoretical categories emerge from data analysis and then the researcher gathers data to fill out the properties of each category (Charmaz 2017). In this research the theoretical properties emerge from the coding process and the data used to explain the properties of each category are quotations taken from male stories of breast cancer. The rationale for using Grounded Theory for analysis is, that although I can claim agency for breast cancer experience, my positioning and personal associations with breast cancer are different to a male patient, so a rigorous method of analysing the male stories was essential to increase awareness of the male authentic voice and validate the research.

My key research method involved collecting Autoethnographical representations, stories from male patients, and analysing these stories through the process of Grounded Theory, I translated their lived experiences into visual and oral storytelling so that the knowledge gained may be communicated to others. Through rigorously analysing and sharing the male breast cancer stories, I record the actuality of the disease, these stories sit within my own experience and my interactions with male patients (particularly Fincher and Ritchie) was the catalyst for this research. Another dimension to the creative outcomes is the incorporation of medical data such as the percentage of men diagnosed in Australia in one year, which reinforces the actuality of the numbers of male diagnoses (Cancer Australia 2021). By using metaphorical images aligned with the quantitative data, a viewer can visually see how many men are affected in Australia in one year, this allows the audience to digest the gravity of the erasure of men in this national conversation.

## 4.4. Autoethnography

Autoethnography in this research relies on the definition by Butz and Besio (2004, p. 353), where research subjects represent themselves through written stories and video interview with me, the researcher. This methodology essentially combines autobiography and ethnography (Ellis, Adams & Bochner 2010, p. 273) to develop accounts of people's lives. In this research I use Autoethnographical representations, written stories, and video interviews, as documentation of the lived experience of breast cancer patients (Decker 2018, p 47) and reflect on these stories (Butz & Besio 2009, p. 1666). Autoethnography is, therefore, concerned with personal experiences to describe and critique cultural beliefs (Adams et al. 2014, p. 1). The researcher may be an *insider* or *outsider* of the group that it is being studied (Ellis, Adams & Bochner 2010, p. 275) though I assert that I am both and as such non-binary. Within this research, the Autoethnographical approach is considered through the collection of stories, interviews by participants and the artworks created in response to my interaction with participants which are then analysed using my modification of Ground Theory coding.

The insights gained from reading 167 men's personal breast cancer stories on the MBCC (2021) website (some of whom are now deceased) was a powerful indicator of how I responded in the creation of my artworks. My own agency as a breast cancer survivor very much informed how I read and responded to their autobiographical stories, which made me think about how I used my own autobiographical influences in the work I was creating. The written stories from the MBCC were significant as men are reluctant to share their experience (Donavon & Flynn 2007, p. 465), by analysing the written stories as well as the personal interviews I could achieve a broader picture of the issues that male breast cancer patients face. Autoethnography is an approach to research which systematically describes and analyses personal experience to understand a particular cultural group (Ellis, Adams & Bochner 2010, p. 273). In the case of this research the cultural group are men who have experienced breast cancer. It is a qualitative methodology where the researcher immerses themselves in the community to gain and understand about experiences rather than general knowledge about the group (Adams et al. 2014, p. 21).

The tenets of this approach value narrative and storytelling, in order to have a connection within a group or an insider status, with a commitment to be ethical and responsible in gathering data (Adams et al. 2014, p. 25). The narrative or storytelling in this research is manifested within the written stories, video interviews and visual images created by the participants or as a response to the stories that are told. The stories recollect memories and feelings after an experience of breast cancer; the dialogue can be very intimate, so the researcher needs to be ethical and responsible in their approach (Ellis, Adams & Bochner 2010, p. 275). The interviews from participants are interactive conversations (Ellis 2016, p. 679) as I wished to create an emotional connection between the viewer and the male breast cancer patients, I aimed to establish an intimacy, similar to artworks such as Intra Venus (1993) by Hannah Wilke (See Figure 3.10, Chapter Three). By analysing the autobiographies from the MBCC (2021) website, I applied the coding of Grounded Theory to discover what issues male breast cancer patients may face. It is by sifting through their experiences and collating common themes that a clearer picture of their concerns was documented.

The process of gathering Autoethnographical representations can be undertaken as an observation of culture or interview with members of a cultural group and includes amalgamation of research through other media such as photos, text or movies (Ellis, Adams & Bochner 2010, p. 276). The researcher analyses the data and writes epiphanies that stem from interaction with members or research (Ellis, Adams & Bochner 2010, p. 275). Any similar repeating feelings from the stories are assembled into categories and evidenced by field notes, or in the case of this research, key phrases or quotations from written stories. Artefacts created by participants or by me in response to interaction with male breast cancer patients or transcript quotations from recorded interviews may also be included as data (Adams et al. 2014, p.77). This methodology aligns with the principles and data analysis of Grounded Theory (Charmaz 2008, p. 166). The categories were described as "thick descriptions" of a culture to help with understanding for *insiders* and *outsiders* of a cultural group (Ellis, Adams & Bochner 2010, p. 277). In the case of this research the category descriptions were synonyms of the category name or direct quotes which provided this "thick description". For example, in Figure 5.11 (Section 5.5.4) "Manogram" is a descriptive category which calls for the language associated with breast cancer to have a "masculine" name change to reduce the stigma for men (Barnes cited in MBCC, 2021).

The Autoethnography in this research relies, in part, on the autobiographies of the male breast cancer patients who retell their lived experiences for other male breast cancer patients on the MBCC (2021) website. This methodology allows me to activate my arts practice by interviewing male breast cancer patients, reviewing written stories and including research through other media such as photos, artwork, text or video (Robson & Sumara 2016, p. 617). There was also the possibility of Autoethnographical representations in visual modalities, as some participants created their own artworks (Ellis, Adams & Bochner 2010, p. 251). As Robson and Sumara (2016, p. 617) explain, the inclusion of participants' own creative work has the potential for a project to create social change from an individual level to the broader community. These include the autobiographies of male breast cancer participants (Fincher and Ritchie), stories from the MBCC (2021) website, and any created artwork to these men telling their experiences of breast cancer on their terms. This approach aligns with the contestation of breast cancer as a female disease so that men can reclaim their sense of masculinity (Donovan & Flynn 2007, p. 464).

The underlining strategy of this methodology is to collect Autoethnographical representations from the research participants so that a new understanding of male breast cancer patients may be rendered as new artworks and/or artefacts. Textual stories from the MBCC provide opportunities for Autoethnographical representation, and the analysis of this data was documented in calligraphy in the *Coding Journal* 2020-2021. I analysed 167 stories and compared my findings to the 28 participants in the research of Thomas (2010, p. 32) and 30 participants in Donovan and Flynn (2007, p. 464). I aimed to provide a broad and current picture of the male experience of breast cancer, and I also wanted to see if awareness had improved over time. Finally, interviews and creative outcomes provided opportunities to articulate a male breast cancer experience, which in turn, may be used to educate others and advocate

for inclusive representations of breast cancer (interview transcripts and transcripts of edited videos from my interviews are contained in Appendix B). This combined methodology can be extended to storytelling for other minority groups including for a range of other social and medical issues.

I understood my role as paying attention to, respecting and celebrating all male breast cancer participants' self-representations (Butz & Besio 2004, p. 1661) as well as my own production of creative material. It is a strategic and unique strategy to insert their voices into the body of works that will be created as male breast cancer is currently underrepresented (Thomas 2010, p. 34). Interaction with male participants and the inclusion of my own story situate me as researcher within the field of breast cancer patients (Choi 2016, p. 28). Autoethnography allows for my "insider-ness" to be used as a methodological and interpretive tool. My Artist Journals (2018-2020; 2020-2021) document my reflections and epiphanies through my engagement with male breast cancer patients. The rationale for using a variety of methods is to provide credibility to research and ascertain any theoretical categories in the research (Charmaz 2008, p. 163) meaning that a variety of methods may be incorporated to contradict or support my assertion that the current paradigm of breast cancer awareness is causing marginalisation of male patients (Robson & Sumara 2016, p. 617). This research is a practice-led where the modalities of creative outcomes are in visual and oral storytelling. My artwork encompasses many different modalities as I am a multi-disciplinary artist which allows for multiple platforms of engagement by the audience of my artwork. Through analysing the stories and articulating the findings in discursive text I planned to publish my written work and exhibit the creative outcomes to raise awareness of male breast cancer.

## 4.5. Grounded Theory

I employed a Grounded Theory methodology (Charmaz 2008, p. 155; Goulding 2002, p. 11), the emergent quality of the research means that questions are derived from the data that I code throughout my making phases of the project (see Table 4.1 below). My methodological approach to making art involves collecting, analysing and translating 167 Autoethnographical narratives, which was the number of Australian men diagnosed in 2020 (Cancer Australia, 2021). By employing a variety of oral and visual modalities, it enabled me to transfer and apply findings through

these processes in a tactile and visible manner. This artistic engagement of data analysis using Grounded Theory allows a multifaceted interrogation of current research to gain a richer understanding of male lived experiences and is also an innovative way to apply and represent emerging findings from this study.

Grounded Theory is defined as an emergent methodology which allows for knowledge to unfold during the research process (Goulding 2002, p. 41). The process is a systematic approach in collection and analysis of qualitative data to develop theoretical categories (Charmaz 2008, p. 161). In turn, Grounded Theory is inductive and open-ended rather than focusing on a result (Charmaz 2008, p.162). This methodology was appropriate for this research as it assumes that little is known about the subject and relies on the immersion of the researcher in the field of study (Charmaz 2008, p. 155). Data collected may be primary or secondary; Walami and Cleland (2015) define primary data as face-to-face contact with subjects, while secondary data are historical or other already-existing texts. Primary data was collected using video interviews of two principal participants. I also included the Artist Journals which I created between 2018 to 2021 to document my encounters with male breast cancer patients; it recorded my observations, reflexive thoughts about male stories and literature review as well as creative outcome ideas. The primary data also forms part of the creative work that I develop while collecting the secondary data sets.

Secondary data is used to replace missing knowledge while preserving the primary data (Walami & Cleland 2015, p. 13). As mentioned in Section 4.1, this research has two principal participants, Rod Ritchie (2015;2019, pers. comm., 27 November) and Rob Fincher (2016, pers. comm., 14 February), plus another 165 male experiences were extracted from the MBCC (2021) website-published survivor stories as men are reluctant to share their breast cancer experience (Donovan 2007, p. 468). The secondary data was the written stories and photographs of male breast cancer patients who shared their stories on the MBCC website (MBCC, 2016) and research papers where knowledge in the form of statistics relating to the male cohort are included in my creative data sets (refer *Artist Journal* 2018 – 2020). The data from government websites relating to breast cancer statistics have been documented in my *Artist Journal* (Cancer Australia 2021; NBCF, 2019). Triangulation is the

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practice of using multiple sources of data to ensure credibility (Belluigi 2009, p. 704), and I use this to substantiate my key data sets and corroborate the authenticity and validity (Peters 2016, p. 144) emerging from my research. My research intent is to verify the authenticity of the creative outcomes by using data analysis and the synthesis of this (see Figure 4.6) into presentational (artworks) and discursive text for the exegesis.

I use coding methods from Grounded Theory to analyse and explore themes emerging from the collected stories and participant video interviews to help me consolidate my research questions. Rather than analysing data for only themes, I sought actions which might align with the method for analysing the stories and video transcripts following the guidelines suggested by Charmaz (2008, p.163). The theoretical categories that emerged were documented throughout the process. Grounded Theory allows for theoretical categories to emerge from the data to help strengthen the emerging research question; these will be discussed in the Findings in Chapter Five.

#### 4.5.1. Grounded Theory coding examples

In my art practice, I engaged with data coding based on Charmaz's (2008) discussion of Grounded Theory and the following explains how I coded the data and incorporated it into my artworks. The process of coding starts with an initial reading. It is an initial reading where there are no preconceived ideas about what to expect (Charmaz, 2008, p. 164). Specifically, I was looking for themes or actions, that arose during the initial reading of the male stories of breast cancer; these were documented in my *Artist Journal* (2018-2020) (see Figure 4.1).

Khevin Barnes diagnosis age: over 60; 2014 themes: cancer has created a need for compassionate comataderic. oless than 1% brotherhood of male breast cancer survivors "Spin cycle' in first few months after diagnosis. "conditioned by the attitudes of manliness "stereotyping" oned to bust through the belief that we are somehow less manly orecipient of brow-lifting expressions, gasps of disbelief, and discomfort information scarce, little historical medical data. ounderfunded • Wimp Factor: difficult to speak up. by time discovered often late stage owife insisted on investigation •Rename proceedure to man-o-gram · Need to self examine -early detection story summary : bust through the stereotyping and have a man-o-gram.

Figure 4.1: Example of initial reading of male breast cancer story from MBCC

Alyson Baker Artist Journal (2018-2020, p. 37)

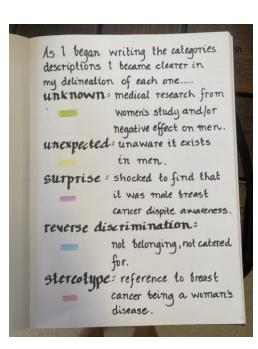


Figure 4.2: Example of assigned theoretical categories and colour coding

Alyson Baker Artist Journal (2020-2021, p. 32)

Once I had read 24 male breast cancer stories, I noticed the same themes kept occurring. Charmaz (2008, p. 167) terms this as "saturating the analysis", whereby theoretical categories may be established. It was through the initial reading of male written stories and video transcripts that common themes began to emerge, and I identified eight umbrella theoretical categories: *Unknown, Unexpected, Surprise, Stereotype, Reverse Discrimination, Manogram, Pink Unicorn,* and *Secret.* I assigned each category a colour. To create a consistency in analysis, I used the colour-coding system to analyse 167 male breast cancer stories including video transcripts, this is illustrated in Figure 4.2. I was inspired by reading an example from Charmaz (2008); however, I have adjusted the guidelines to suit my artistic practice where I describe the categories in dictionary meanings or direct short quotations from the data rather than thick descriptions (Ellis, Adams & Bochner 2010, p. 277). Evidence for each category was then documented in calligraphy in my *Coding Journal* (2020-2021).

A coding method was applied to the analysis of data sets so that a uniform system was used throughout the research process. This is exemplified in Table 4.1 (see below) and illustrated with the Figures 4.1 - 4.6. Table 4.1 shows the dates that the analysis was conducted, what process was used and documents succinctly the emerging knowledge.

Date of	Data coding	Data analysis	Emerging
analysis	stage	process	knowledge
27.09.2019 – 31.12.2020	Initial reading See Figure 4.1	Main issues faced by patients documented in calligraphy in Artist Journal	Identification of eight theoretical categories: Unknown, Unexpected, Surprise, Reverse Discrimination, Stereotype, Manogram, Pink Unicorn, Secret
31.12.2020 – 4.05.2021	Assigning categories and colour-coding Figure 4.2	Colour-code written stories	Findings Chapter Table of Theoretical Category Frequency ( <i>Artist Journal</i> (2020 – 2021, p. 58) (Refer Appendix C)
31.12.2020 - 7.05.2021	Colour-coding of discursive text (see Figure 4.3) and motifs for presentational text. (see Figure 4.6)	Reading written stories, video transcripts and artwork emerging from interactions with participants. Colour-code texts to identify categories. Assign categories from textural analysis where applicable or define new categories as they emerge.	Verbatim text relating to each category is documented in calligraphy in <i>Coding Journal</i> (2020 – 2021). Motifs in representational artwork defined and new categories documented in <i>Artist Journal</i> (2021) (see Figure 4.7)
31.12.2020 – 2.05.2021	Category definitions See Figure 4.4	Dictionary research to find synonyms or direct quotations from secondary data to describe each category	Category descriptions documented in calligraphy in <i>Coding Journal</i> (2020 – 2021)

 Table 4.1: Data analysis of stories of male breast cancer 7/09/2019 – 07/05/2021

Date of	Data coding	Data analysis	Emerging
analysis	stage	process	knowledge
31.12.2020 - 2.05.2021	Category evidence See Figure 4.5	Evidence of each category is documented in quotations written in calligraphy	Appendix C Theoretical Category Frequencies Artist Journal (2020 – 2021, p. 58) Tamoxifen Unknown, Artist Journal (2020 – 2021) p. 35 Diagnosis Timing, Coding Journal (2020 – 2021) p. 52
31.12.2020 - 10.04.2021	Findings from data analysis See Appendix C from <i>Artist</i> <i>Journal</i> (2020 – 2021, p. 58)	From the tables constructed during the documentation of Category Evidence new knowledge is induced	Data from analysis to be included in future journal articles for health Journals. (Refer Appendix C). Data incorporated in artworks in the form of verbatim discursive text (See Figure 4.6).

Once I had established the eight categories and assigned a colour-coding system, I conducted a focused reading where I reread the 24 stories from my initial readings and downloaded more stories from the MBCC website (MBCC, 2016) and so with the two video interviews I had a total of 167 stories. I colour coded the stories to identify the categories as exemplified in Figure 4.3. I made calligraphy category headings in a *Coding Journal* and wrote a definition for each category (see Figure 4.4).

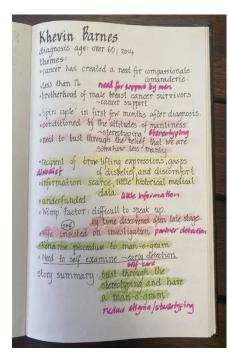


Figure 4.3: Example of colour coded story to highlight the categories established in this research

Source: Alyson Baker Artist Journal 2018 – 2020, p. 37.

In the *Coding Journal* (2020-2021), I collated evidence, direct quotes from the male breast cancer survivor stories from the MBCC (2021) website and documented these in calligraphy (see Figure 4.5). As Charmaz (2017) describes how the researcher gathers data to fill out the properties of theoretical categories, in my research I used the raw data of quotations from written stories and video transcripts of male breast cancer patients. I also used the direct quotations to tally the frequency of phenomena, to collate empirical data collected during the analysis process, for example in 44 out of 167 (27%) stories the authors did not know that breast cancer occurred in men. I made tables and collated statistics about male breast cancer (see Appendix C). In some cases, the direct quotations under theoretical categories were used to create artwork for further analysis (see Figure 4.6). The quotations used in the creative outcomes were selected because they represented common themes in each category of my data analysis.

1× mill Quinze EREI breast cancer is a "woman's disease"

Figure 4.4: Theoretical category and definition example: Stereotype Source: Alyson Baker Coding Journal 2020 – 2021 (p. 49).

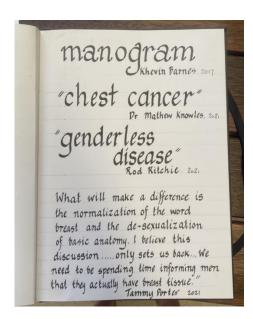


Figure 4.5: Evidence of category using direct quotations, example: Manogram Source: Alyson Baker Coding Journal (2020 – 2021, p. 49).

I created motifs for the stereotypes where the text was embossed on copper sheets, the layout in Figure 4.6, for example, reflects the question mark motif I assigned for the category of "Unknown", the visual motifs for each category are documented in *Artist Journal* (2020-2021) and discussed in Chapter Five (Section 5.3.2 and exemplified in Figure 5.6). Finally, I articulated the findings into artworks for exhibition, and distribution to breasts cancer agencies and clinics. In Figure 4.6, I exemplify how I used direct quotations from my data analysis, the text in this case was the material for the artwork.

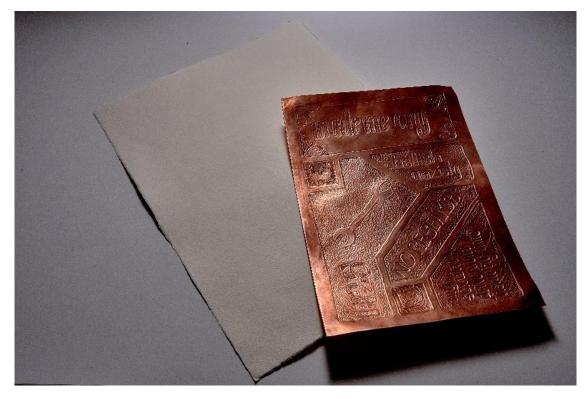


Figure 4.6: Direct quotations from *Coding Journal* 2020 – 2021 (pp. 3, 4, 6, 10) and Cancer Australia statistic 1:125 (2016). Source: Alyson Baker Stereotype Unknown (2021)

The challenge for me was how to code in a way that could be transformed from the discursive into the representational text. To enable this, I developed my own system of finding symbiotic elements in the images and gave them a category so that I could collate this set data analysis with the text analysis of written stories or transcripts from videos. A strategy I used to code the artworks was to firstly denote motifs within the artwork (see Figure 4.7). Artworks were then analysed using a method of assigning common headings which would enable me to use a reflexive practice to allocate existing categories where applicable or create new emerging categories (see Figure 4.8).

Representational Analysis motifs 2000 U bra / spanner nipple-less kniited breasts yarn 1=125/1=119 164/167

Figure 4.7: Example of Representational Analysis motifs Source: Alyson Baker *Artist Journal* (2021, p. 1)

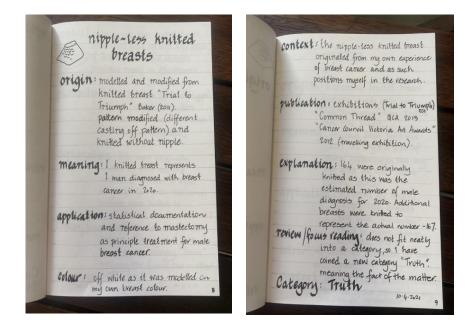


Figure 4.8: Exemplifier of analysis of artwork Source: Alyson Baker *Artist Journal* (2021, pp. 8-9)

After I coded the data for actions, themes, or motifs, I then grouped these into theoretical categories (Charmaz 2008, p. 167). I was able to cross check this with the knowledge I had gained in the Literature Review (Chapter Two) to interrogate my research questions. These theoretical categories were able to be analysed through reflexive practice and reflection upon other literature evidence to confirm or deny my assertions. By using a diversity of data sets (which is a hallmark of Grounded Theory), I was able to enhance my initial research "hunches" as this provided a triangulation (Peters 2016, p. 144) of analysis to anchor authenticity and validity to the research. From this focused analysis, I induced an explanation as to why certain phenomenon occurred. I collated the frequency of the theoretical categories to prioritise importance for my creative outcomes.

The findings from my data analysis are used either verbatim or as inspiration to make artworks, and this provides further data for discussion in the Findings in Chapter Five of this exegesis. For example, after reading that 1 in 125 breast cancer patients are male (Cancer Australia, 2021) I could create the background image for the watercolour portraits of my participants; a blue spanner among 124 pink bras (See Figure 5.12 in Chapter Five). The findings from my data analysis were reflected upon to verify or contest my assertion that male breast cancer patients are

marginalised and that this relates to their poorer prognosis compared to women. The data analysis resulted in my creative responses to the retelling of their experience by participants in the research and from written autobiography from male breast cancer patients.

## 4.6. Methods of data collection

Within this study, I have used a variety of methods of data collection to correspond with my own multimodal practice. The following explains and exemplifies the data collection methods in this research.

#### 4.6.1. Pre-study and principal participants

The principal participants in this research were two men that I video interviewed during my Honours research (2015-2016), what I refer to as my prestudy for this research: Rob Fincher, since deceased, and Rod Ritchie, survivor. Fincher and Ritchie are pivotal to this research as they were the only men ever in Australia to be included in the National Breast Cancer Summit in 2017, which was run by the Breast Cancer Network Australia (BCNA), the agency that advocates for better conditions for patients. It is interesting to consider that no other summit has since been organised. The BCNA invited these men to attend in a cohort of 200 participants and they were the only male voices at the 2017 Summit. At the 2017 summit, they were able to express their concerns and since then the BCNA has conducted some research into male breast cancer (BCNA, 2019). Their vocal presence has seen breast cancer agencies taking a more inclusive approach to the representation of the disease but as Ritchie (2019, pers. comm., 27 November, p. 12) explains in his video interview "we need to feel part of the cohort, we need to feel accepted as men with the disease".

One potential participant was undergoing very invasive treatment for terminal breast cancer and his illness prevented him from participating. I engaged with the stories published in the MBCC (2021) website to gain a broad perspective of male breast cancer experience. As my research progressed, I contacted the USQ Ethical Review Committee to include my pre-study video and photography to incorporate female images in my inclusive representation of the disease, this was approved in amendment version two of my Ethical Review application. I also conducted periodic interviews with Rod Ritchie, to document vignettes (Humphreys 2005, p. 842) of experience and to observe any changes that may occur in male breast cancer awareness over time.

#### 4.6.2. Verbatim online material

I collected written stories, photos, and artworks from the MBBC (2021) website. As this is a published public website, I did not require consent. However, I liaised with the MBCC administration team and have shared my creative outcomes from analysis and translation of the male breast cancer stories to increase the visibility of my work by using their platform and so that they can use my work as an educational resource. It was pivotal to use the MBCC written stories as they provided a larger cohort for data analysis and created a validity and cross check to the information that I had gathered during the interviews with Ritchie (2015 pers. comm., 11 September; 2019 pers. comm., 27 November) and Fincher (2016 pers. comm., 14 February).

#### 4.6.3. Artist Journals (2018-2020; 2020-2021)

Throughout this research I have created Artist Journals. The Artist Journals (2018-2020; 2020-2021) document my emerging ideas developed through reflexive practice from my engagement with breast cancer patients, medical experts and literature about breast cancer. Chiefly, this is a reflective journal that interrogates information from medical experts such as Whiteside (2017) to validate the credibility of collected stories and ascertain any discrepancies in the current public paradigm of breast cancer awareness (Choi 2016, p. 31). This is where I sketch ideas, inspired by my interactions with participants, from readings, from statistical information. It is a reflection on my practice, sometimes musings from information that I am finding. On other occasions, I reflect on my own experience of breast cancer. I question current information when I find contradictory information in journal articles or words from lived experiences that lead me to research the facts. For example, Fincher (2016, pers. comm., 14 February), in his interview, questions whether medically male breast cancer should be treated differently to women's. In response to this comment, I started to research medical articles in an attempt to find an answer to this question, which in turn refuted Whiteside's (2017) statement that male breast cancer has a

poorer prognosis than women due mainly to awareness, this is explored in the Findings section of this exegesis (Chapter Five Section 5.2).

The *Artist Journals* (2018-2020; 2020-2021) are handwritten in calligraphy and have illustrations of creative ideas throughout as they act as a form of documentation and an artwork. I first began using calligraphy to record my artistic practice and musings from readings during my Honours research. It was in the process of writing in calligraphy that I found therapeutic usefulness for my own recovery from breast cancer and the trauma I was experiencing at the time. I used the musings and sketches to create ideas for artwork and some sources of writing for the Confirmation document.

The *Artist Journals* (2018-2020; 2020-2021) document ideas developed through reflexive practice from my engagement with breast cancer patients, medical experts, and literature about breast cancer. This journal interrogates information from medical experts such as Whiteside (2017 pers. comm., 17 November) to validate the credibility of collected stories and ascertain any discrepancies in the current public paradigm of breast cancer awareness (Choi 2016, p. 31). These personal *Artist Journals* document my ideas for creative works, it is where I make links between stories, advocacy, and medical knowledge. Also, epiphanies and reflexive thoughts (because I transformed throughout this research process) from my analysis are documented in *Artist Journals* (2018-2020; 2020-2021). Visual images from my reflection on the data I collected was documented and, in some cases, these were added in the creative works which are described in Table 4.1.

## 4.6.4. Coding Journal (2020-2021) and Artist Journal (2021)

The *Coding Journal* (2020-2021) documents the eight theoretical categories that were established during the data analysis of written stories and video transcripts from men with breast cancer. The *Artist Journal* (2021) documents the representational analysis of artworks that emerged during the research period and included some pre-study video.

The *Coding Journal* (2020-2021) includes the data analysis of 167 written stories, including video transcripts from two principal participants. I established eight categories as evidence to substantiate each category, which were documented in calligraphy under each category heading and description. In this research the evidence of each category was direct quotations from written stories and video transcripts. The direct quotations were tabled to record the frequency of phenomenon within each category. For example, in 167 stories 75 explicitly mentioned that they were prescribed Tamoxifen as a hormone therapy. Of these 75, five questioned whether it was appropriate to prescribe a drug for men which was designed for premenopausal women. Verbatim quotations were also amalgamated into creative outcomes. However, there was some information which provided statistics which will be useful for future publication in medical journal articles and knowledge to be shared with breast cancer agencies.

In the *Artist Journal* (2021), I coded the representational artwork that was developed during the research period. The theoretical categories established during the written story analysis were used to group artwork. In some artworks they did not fit neatly into the same categories as the written stories, so additional theoretical categories were established. The artwork was analysed by breaking down the images into visual motifs or explained in terms of the symbolic elements. Additional categories for the representational text emerged, for example, the background to the watercolour paintings were inspired by the statistic that one in 125 breast cancer patients are male (Cancer Australia, 2016), this alludes to the fact or truth of the situation, so a new category of "truth" was established to define the artwork.

# 4.6.5. Qualitative and quantitative data for incorporation into artwork

As discussed previously, during my Honours research I discovered that one in 125 breast cancer patients are male (Baker 2015-2016) so I wished to explore the amalgamation of quantitative data into my artworks as this has become a mainstay of my arts practice. I interviewed Eliza Whiteside (2017, pers. comm., 17 November), breast cancer researcher, and reviewed statistics of male breast cancer occurrence in Australian men (Cancer Australia, 2021) and conferred with BCNA and NBCF websites (BCNA, 2021; NBCF, 2021). The knowledge I gain from this medical insight was documented in my *Artist Journal* (2018-2020) and contextualised in the artworks. Quantitative analysis of male breast cancer patient mortality compared to female was used to verify or deny that men are more 'at risk' of developing later stage cancer than women (Cancer Australia, 2021). Research from other authors who have conducted qualitative research about male breast cancer revealed contradictions or support for the notion that male breast cancer patients are marginalised and, if so, how (Donovan & Flynn 2007, p. 467). In the Literature Review (Chapter Two) I discuss the marginalisation and stigma for male breast cancer patients; not only that they are a minority, but health care facilities, representation of the disease and medical treatment is biased toward female patients (Donovan & Flynn 2007, p. 466). I also used artistic strategies identified in the Literature Review (Chapter Two) to incorporate in the artworks; these acted as subversive strategies to destabilise the current paradigm of breast cancer awareness.

#### 4.6.6. Creative work

Using different modalities, I created 202 artworks which best represented the concepts I wished to expose and articulate as key outcomes of this research. For example, by amalgamating the fact that 167 men were diagnosed with breast cancer in 2020, it was the exact number of knitted male breasts that I created. During my research I wanted to define the notion of "stereotype" and discovered that it also is a term which also refers to a modality of print making; and this print method is used to represent the theoretical categories of this research. I inverted the artistic concepts of *erasure*, to create *illumination* where invisible ink was used in a palimpsest and black light illuminated the ink, uncovering the hidden feelings of male breast cancer patients. The rationale for using different modalities was that each served a specific artistic message in the selection of its material and process. This is discussed in detail in the concept of *othering*, Chapter Two Literature Review (Section 2.2.3) and how I respond in artwork in Chapter Five, Findings (Sections 5.6 and 5.8).

#### 4.6.7. Video and photography

I used video and photography to document the interviews with participants in my pre-study and DCA research. I also used video to record the processes of making artwork such as knitting and printmaking. The process videos were used to make other artworks and were included in a digital creative portfolio of this research. It became necessary to document my practice and processes as some footage and photography was used to create other artworks. For example, the knitting process video was used in two creative outcomes: *Manogram* (2020) video and a USQ video competition *Visualise Your Thesis* (2021), these videos are in the creative portfolio. In some cases, the data collection process is made into a visual artefact; for example, I made a video of the printing of the *Stereotype* (2021) series to make the *Flong* (2021) series; although this video did not become part of the final exhibition it is documented in the creative portfolio.

#### 4.6.8. Gallery exhibitions

As a practicing artist and researcher, it is necessary to exhibit my artwork as a means to promote public awareness of male breast cancer. As a researcher, it is also a way to publish the findings of my investigation as a form of further disseminating to a scholarly audience and to share with breast cancer agencies such as BCNA. For this research, I secured exhibition space on the Gold Coast (16 October 2021) and Toowoomba (December 2021 and January 2022). The Gold Coast exhibition was attended by 60 people, and I received unsolicited feedback which is contained in Appendices G1 and G2. The Toowoomba exhibition in December 2021 was well received by the curator at USQ, and I have been invited to exhibit this work at USQ's new gallery in 2023 (B Taylor 2021, pers. comm., 30 November).

### 4.6.9. Semi-structured interviews

During the process of gathering information, I met with or communicated via Zoom, with medical experts Dr Eliza Whiteside, breast cancer researcher, and Prof John Boyages, radiation oncologist and author of *Male Breast Cancer: Taking Control*, the conversations were not recorded but information gleaned from these personal conversations have been included in this research. Similarly, during my prestudy I met with Haya Cohen, textile artist, and Patricia Wise, breast cancer survivor, these people have also been cited as personal communication in this exegesis.

## 4.7. Art-making processes

Nine types of artmaking processes emerged over the three and a half years of this research project. These processes are listed below and the timeline to produce the creative outcomes and documentation in exegesis are recorded in Table 4.2 Phases of Research (2016-2021) below.

- Audio contained in the video of the knitting process: the audio element taken from captured video of male breast cancer patients
- ii) Watercolour paintings
- iii) Photography
- iv) Video
- v) 167 Knitted Male Breasts Art Forms
- vi) Calligraphy

- vii) Copper Plate Stereotypes: Eight embossed copper plates with direct quotations from *Coding Journal* (2020-2021).
- viii) *Flong:* Eight water colour paper embossed printing of stereotype copper plates.
- ix) Drawings: Eight palimpsest drawings of invisible ink calligraphy drawn over with watercolour pencil.

## 4.8. Phases of creative work

This research was divided into three district phases: pre-confirmation, postconfirmation, exhibition for final assessment and publication, across a period of time starting in July 2018 and culminating in the exhibition and assessment in October 2021. Each phase was planned, and time scheduled so that a finite completion to the research was achieved. A creative and exegesis timeline was formulated in the initial research period to facilitate the completion of both artwork and exegesis within the time limits of a Doctor of Creative Arts program (Refer Appendix D). The following phases of research describe the creative process and are arranged in chronological order.

#### 4.8.1. Phase 1: Pre-Confirmation

This section outlines the artistic processes of making, literature review, artist audit and ethical review applications needed to facilitate my confirmation of candidature. As this phase included some pre-study artwork, it spanned from March 2015 - 4 November 2019.

Some of the data was pre-study which I collected during my Honours research at QCA Griffith University between March 2015 and October 2016. My meeting with principal participants Rob Fincher and Rod Ritchie became the catalyst for this research and as such photographic images and audio from the interviews taken in 2015 and 2016 inspired some of the artistic responses in this Doctor of Creative Arts. Another interview was conducted with Rod Ritchie (2019, pers. comm., 27 November) to ascertain if there was any change in awareness since my interview with him in 2015. The first action in my DCA research was to conduct an artist audit concerning breast cancer in contemporary art, both nationally and internationally – streamlining the influential artists who inspired my creative responses. From this initial audit I selected the pivotal artists who have influenced the creative outcomes of this research. The review of artists can be found in Chapter Three.

I began making knitted breasts, this method was used in my undergraduate studies (2011-2013) as the knitted breasts documented my experience and had been developed in my practice over a number of years. The small, knitted breasts in this research are a motif, a symbol, for one man who had experienced breast cancer. After reading the statistics that estimated 164 men will be diagnosed with breast cancer in 2020 (Cancer Australia 2021), I set my self the task of creating this number of breasts. The creation of 164 breasts spanned over the pre-confirmation to postconfirmation time period, and the number expanded to 167 when more current information became available (Cancer Australia 2021).

I began researching for my literature review and, under the guidance of my supervisors, established my key theoretical anchors which are the challenges men with breast cancer face: social stigma due to gender stereotyping of breast cancer, contested masculinity, and marginalisation. The central concept underpinning this research is that male bodies are a transgressive embodiment of breast cancer (Richardson, 2016). I assert that male breast cancer experience is abjected (Rudge & Holmes, 2010), and marginalised (McQuarrie, 2012) leading to trauma (Leys, 2000). The idea of living with what is considered a feminine disease is distressing and stigmatising for some men (Donavon & Flynn, 2007). This is discussed further in the Literature Review in Chapter Two.

I completed my Confirmation of Candidature on 4 November 2019 when I presented my findings to the Confirmation of Candidate panel. The panel provided feedback particularly on the concept of masculinity and questioned the diversity of gender in my research. This was the impetus to research about masculinity and breast cancer in transgender patients. Rob Fincher (2016, pers. comm., 14 February) also wondered if there would be people other than males and females who are not included in the representation of breast cancer. I reviewed the medical marginalisation of patients other than females; this is described in Chapter Five

Findings (Section 5.2). With this in mind I approached Terry Dactyl and Justine Case, drag performers, to ask if they would participate in an information video about breast cancer, they initially agreed but finally declined to participate.

#### 4.8.2. Phase 2: Post-Confirmation

After Confirmation of Candidature, I spent time exploring creative modalities inspired by my interactions with the participants. I reviewed the video footage and made transcriptions for analysis. I highlighted critical verbatim text that could be captured in audio. In collaboration with a filming and editing studio (Desert Island Media), they captured video of me knitting the word *monogram* in yarn into one knitted breast. This footage was edited, and the background audio was derived from edited video of my two principal participants. This video, *Manogram* (2020), became part of my exhibition installation of knitted breasts.

The *Artist Journals* (2018-2020) and (2020-2021) were continually added to during this time. I reflected on my exegesis research and writing process and made prototypes for artwork. I also experimented with a variety of calligraphy so that I could use textural art as one of my modalities for the creative outcomes. I also created two other journals, *Coding Journal* (2020-2021) and *Artist Journal* (2021) these journals document the data analysis of discursive and representational text.

I made watercolour paintings of my principal participants and a young female, to create an inclusive representation of breast cancer. I contacted Rod Ritchie for review of the artwork that I was creating. As Rob Fincher had passed away in 2019, I contacted his widow for review of the artwork that was emerging (see Appendix H5 & H6). I experimented with ways to exhibit the 167 knitted breasts and brainstormed ways to incorporate interaction with the artworks so that viewers of the work could engage in a tactile and tangible way. I documented the various ways I could present the artworks and documented options in my *Artist Journal* (2018-2020; 2020-2021).

During my analysis of stories, I also developed a system of documentation of the emerging categories in drawing, which I then experimented with invisible ink, and stereotype embossing. This was amalgamated into the installation and provided a textural element to the discursive text. I also reviewed videos that had been previously made during coursework as audio for the *Wishing Star* (2016) installation

at the Gold Coast Arts Centre and I used the video snippets to create a video called Conversations (2016). Conversations (2016) and Manogram (2020) were analysed using representational data analysis using my adaptation of Grounded Theory. The videos Conversations (2016) and Manogram (2020) were included in the final creative outcomes (see Findings Chapter Section 5.5.3; 5.5.4). I discussed with Prof. John Boyages (2021, pers. comm., 1 March), radiation oncologist, and collaborator in Poster (2021) on how to use a non-gendered textural reference, wording for signs of breast cancer and we decided on the term "anybody" to provide an inclusive representation (See Figure 5.9), he also reviewed the artwork (See Appendix H1). I also applied and was accepted to give a paper at the Arts & Social Sciences Research: Relevance, Responsiveness and Impact, the 8<sup>th</sup> annual UNSW Arts and Social Sciences conference in September 2020. I submitted a video of my research project for USQ Visualise Your Thesis video competition and presented a speech at the USQ Research Symposium 2021. During this period, I refined and expanded on the Confirmation document to begin writing chapters for my Literature Review and Methodology.

#### 4.8.3. Phase 3: Exhibition and feedback

As I was collating the creative outcomes from this research, I began to plan an exhibition of artworks. COVID-19 (in 2020 and 2021) restricted some viewing of public artworks and as the restrictions lifted, I saw two options for publishing the artwork: through a digital *creative portfolio* (website) and live exhibition. I approached a few galleries that provided facilities to best exhibit my work, there was gallery space available at Karma Collab Hub on the Gold Coast which allowed me to exhibit my work in a public venue where there was an audience with a wide range of academic interests. I observed a high level of interaction with the artworks and received unsolicited feedback both verbally and written responses (see Appendix G1 and G2). I was also able to exhibit at the USQ Arts Gallery foyer (A Block, Toowoomba Campus). This provides an opportunity to raise awareness in the regional communities and was scheduled for exhibition over the USQ Summer School in January 2021. Brodie Taylor, USQ art curator, estimated that a large audience of diverse regional viewers would visit the exhibition. I forwarded *Poster* (2021) to BCNA for advocacy and education. Subsequently, BCNA are going to

publish this artwork in their Health Professionals Network, it may be shared with doctors Australia wide, to download and print for display in doctor's waiting rooms.

From a marketing and promotion point of view I engaged Dr Linda Clark, lecturer in Creative Arts at USQ, to generate a creative portfolio. I also uploaded photos into my Facebook page *Breasts and Chests*. I engaged Mia Huxley, graphic designer, to create an invitation page for the Karma Collab Hub exhibition. Both Karma Collab Hub and USQ were able to assist with marketing the exhibitions, this facilitated an audience of viewers, in addition to my personal invitations to the exhibition. With the physical setup for the exhibitions, I engaged one other person to assist with the installation and deinstallation of artworks and video. I looked at promotion of images and video artwork on my creative portfolio, Facebook page, and distribution of videos to breast cancer agencies NBCF and BCNA. To summarise the process undertaken from pre-study to final exhibition I have collated a graph (refer Appendix D). A detailed time schedule for the research is summarised in my Creative and Exegesis Timetable (refer Table 4.2 below).

During my research, I wondered if participants who shared their stories had any positive outcomes. To evaluate how effective my research was in practice, I conducted exit surveys for my participants to complete. The findings from the research and the feedback from participants is explained in detail in my Findings (Chapter Five and feedback in Appendix E).

To ascertain or deny the notion that sharing stories is beneficial to patients, I researched articles by experts in the field of trauma to see what they suggested. The insights from these readings became the justification for my methodological approach and this was paralleled in my theoretical exploration which is discussed in the following chapter.

The table below outlines the time and phases for the creation of my artworks. It is divided into three stages: Pre-Confirmation, Post-Confirmation and Exhibition. I have added the pre-study section at the beginning as some data and artworks from my Honours thesis have been included in this research. It documents the data collection processes and creative outcomes that emerged during this research, each creative outcome relates to the coding system described in Section 4.5.1 of this chapter and are numbered (i) - (ix). I have also included the timing for the research and writing of my exeges is as this occurred during the process of making artworks.

Phase	Activities	Data Collection Methods	Dates	Outcomes
Pre-study	Recording Rod Ritchie's story	Video Photography (iv)	September 2015	Edited video created
	Recoding Rob Fincher's story	Video Photography (iv)	January 2016	Edited video created
	Isolating audio from video	Edited audio (i)	September/ October 2016	Audio from videos included in soundscape in installation for exhibition and assessment.
	Video from installation Gold Coast Arts Centre 2016	Edited audio (i)	October 2016	Edited video created Audio only has been published (2016)
Pre- confirmation	Knitting male breasts	Making artefacts (v)	September 2018-June 2021	167 knitted breasts
	Literature Review	Literature Review research and writing	September 2018 – January 2020	Literature Review draft for inclusion in Confirmation document
	Methodology Writing	Methodology research and writing	Semester 1 2019	Methodology Paper for assessment and inclusion in Confirmation document
	Recording Rod Ritchie's story update	Video Recording (iv)	November 2019	Edited video for inclusion of audio into video of knitting breast.

 Table 4.2: Timeline of creation of artworks

Phase	Activities	Data Collection Methods	Dates	Outcomes
	Review of pre- study video	Making artefacts (iv)	February – June 2020	Edited video for inclusion of audio into video of knitting breast.
	Documentation of artistic practice	Artist Journal documentation of arts practice (vi)	August 2018 – July 2021	Artist Journals (2018- 2020; 2020-2021)
Post- Confirmation	Research Statement	Making artefacts (iv)	Semester 1 2020	Research statement Collaboration of video editing with Desert Island Media to create video for exhibition and analysis
	Recording knitting process of breast	Making artefacts (iv)	June 2020	Collaboration of video editing with Desert Island Media to create video for exhibition and analysis
	Water colour painting	Making artefacts (ii)	June – October 2020	3 watercolour paintings
	Analysis of male breast cancer stories from MBCC Calligraphy responses	Data analysis (vi) Making artefacts (vii) (viii) (ix)	June 2020 – June 2021	Calligraphy first analysis in <i>Coding</i> <i>Journal</i> (2020 – 2021) Analysis of artwork <i>Artist Journal</i> (2021) Calligraphy in copper for theoretical categories Watercolour paper embossing to create "stereotype" of theoretical categories Male Mammogram drawings and invisible category headings

Phase	Activities	Data Collection Methods	Dates	Outcomes
	Exegesis writing	Research and writing	February – November 2020	Literature Review and Methodology Chapter drafts
		Writing	December 2020-August 2021	Edit Literature Review and Methodology Chapters Introduction and Eindings Chapter drofts
		Writing and editing	September 2021 – November 2021	Findings Chapter drafts Editing exegesis for copy editing
		Editing	November - January 2022	Copy editing and submission of exegesis
Exhibition	Exhibition applications	Gallery application and visits	June 2021- August 2021	Exhibition booking
	Documentation of artworks	Making artefacts (iii)	June 2021	Photography of artworks for Digital creative portfolio
	Catalogue and promotional details for exhibition	Advertising poster and artwork didactics Photographs (iii)	February – September 2021	Advertising posters Website update Social media advertising Distribution of digital artwork to NBCF and BCNA
	Exhibitions	Gold Coast Toowoomba	October 2021 December 2021 and January 2022	Public Exhibition assessment Data taken from October exhibition, audience feedback is included in and analysed in Findings Chapter (Section 5.6)

# 4.9. Summary

Through the analysis of data sets I created artworks that I had never initially considered, this was largely due to the coding process of Grounded Theory using the Autoethnographical representations by male patients. This methodology of combining Autoethnography and Grounded Theory also culminated in the *Illumination* (2021) and *Stereotype and Flong* (2021) series (See Chapter Five). It was through the review of Dan Elborne's *One Drop of Blood* (2013) that I considered including statistics, to create 167 knitted breasts. It was by the slow methodical process of documenting my research in calligraphy that I reflected on the stories I read and was inspired to make *Poster* (2021) (see Chapter Five) which is due for publication with BCNA in February 2022. By creating *Artist Journals* (2018-2020; 2020-2021) I used practice-led research and reflexive arts practice to design and make artworks to raise awareness of the diversity of breast cancer patients. I presented at conferences and entered the USQ *Visualise Your Thesis* (2021) competition so that the message of male breast cancer awareness could be shared.

Through the documentation of my arts practice, I made videos and water colour paintings to include in my exhibitions. The exhibitions were the culmination of this research and were well received by the viewers; the one-night-only exhibition at the Gold Coast was attended by over 60 people, while the Toowoomba exhibition is predicted to attract many viewers. Brodie Taylor, USQ Arts curator has asked that I exhibit this work again in 2023 at the new USQ Arts Gallery in B Block, Toowoomba Campus. More importantly though, the feedback I was given by viewers has highlighted that some people did not know breast cancer existed in men, that the participatory artworks were engaging, and as Robyn Cameron (2021, pers. comm., 16 October), NBCF ambassador explained, she was in awe of the artworks as they were instrumental in raising awareness of the diversity of breast cancer patients. It was through my advocacy for male breast cancer that BCNA will publish *Poster* (2021) as a resource for health professionals across Australia. The creative outcomes that were exhibited are described in terms of the literature review, artist review and methodology in detail in Chapter Five.

### CHAPTER FIVE: CREATIVE ART OUTCOMES AND FINDINGS

This chapter discusses and documents the findings from my research in terms of the ways in which visibility and public awareness could be given to and about male breast cancer. The chapter particularly explores how these awareness strategies and information, including personal breast cancer narratives are articulated into artworks and/or have emerged from my art practice. Within this context, I draw on my own personal experiences of breast cancer as a catalyst in providing a multimodal platform for male breast cancer patients sharing their stories through my art practice. My creative outcomes along with key artmaking processes and journals work as methods along with other supporting materials which are featured in my Creative Arts Portfolio (The Challenge of Pink: Doctor of Creative Arts Portfolio, University of Southern Queensland). My creative portfolio can be viewed at: <a href="https://alybaker.myportfolio.com/alyson-baker">https://alybaker.myportfolio.com/alyson-baker</a>. The findings are underpinned by Autoethnography and Grounded Theory as methodological approaches that assist in identifying how my practice of analysing data sets has been incorporated into the artworks and to articulate how the creative outcomes may advocate for male breast cancer.

This chapter takes on a chronological approach that maps my initial "hunches" of men being marginalised in the representation of breast cancer up to the inclusion of the diversity of people with breast cancer. My creative outcomes and findings address the central premise of firstly exploring the extent to which artworks in the forms of visual and oral storytelling may subvert the current breast cancer awareness paradigm. This will be followed by addressing my creative outcomes as an alternative multi-modal and experiential artistic platform that gives visibility and voice to male breast cancer patients and how my developed practice can advocate for inclusive breast cancer narratives within the broader art and medical communities.

Drawing on data from my coded Journals, inspiration from reading male stories, qualitative and quantitative research about male breast cancer, I establish key findings. This chapter will discuss the key findings in terms of lack of awareness of male breast cancer, the methodological process and emerging artworks, agency, advocacy and inclusion. These key findings are explained in relation to the creative outcomes inspired by theoretical underpinnings (discussed in Chapter Two) and strategies gleaned during my artist review (Chapter Three). I discuss the exhibitions of the creative outcomes of this research referring to viewer feedback and review by participants. In conclusion I remark on the desire by some male patients to rename male breast cancer and make suggestions for future research.

To understand how men with breast cancer are affected, I made artefacts to document how they felt. As I discovered more, I worked through my findings in artworks and some of my creative workings became findings in themselves. In this chapter, I will discuss the data developed from my *Coding Journals* and aspects of my artworks as they pertain to the exploration and manifestation of these findings. To begin the discussion about the findings of this research, I broached the key issue of lack of knowledge about male breast cancer.

## 5.1. Responding to the lack of knowledge about male breast cancer

Drawing on my own medical experiences of breast cancer diagnosis, I began my research exploration with an initial intuitive sense that men were marginalised in the current paradigm of breast cancer awareness. As I began to focus in this area, what I had not expected was the extent of the problem within broader contemporary community/(ies). The information contained in this chapter's key findings extends upon this initial enquiry and considers the consequences of this lack of knowledge for male patients, which are: contested masculinity (J Boyages 2021, pers. comm., 1 March), late diagnosis as men are not aware that they can get breast cancer and thus present later for diagnosis (R Fincher 2016, pers. comm., 14 February), medical research being female-biased, coupled with biological differences in male and female breast cancer (Lordso Rota et al. 2017) culminating in a lower survival for this cohort (Cancer Australia 2021),

In my semi-structured interview with Prof. John Boyages AM (2021), Australian breast cancer specialist, radiation oncologist and author of *Male Breast Cancer: Taking Control*, he stated that the major issue is that a diagnosis of breast cancer contests masculinity itself (J Boyages 2021, pers. comm., 1 March). This is supported by Eileen Thomas (2010) who found that 43% of males in her study would consider a diagnosis of breast cancer as an assault on their gendered self. Boyages (2021, pers. comm., 1 March) links this contestation of masculinity to the branding of breast cancer in pink and the gender stereotyping of the disease as feminine. For some men, this results in concealing their diagnosis (*Coding Journal* 2020-2021, p. 56); not seeking emotional help (*Coding Journal* 2020-2021, p. 56); or covering their scars so that they do not have to "come out" with their experience (*Coding Journal* 2020-2021, p. 57). In one of the stories from the MBCC, Philip Pilato (*Coding Journal* 2020-2021, p. 57) describes how initially he did not tell his family about his breast cancer diagnosis as he was embarrassed and felt people would laugh at him. For example, Pilato said, "it was like my private shame" (*Coding Journal* 2020-2021, p. 57). For some men, it is too embarrassing to disclose their diagnosis, so they make up stories about how they got a mastectomy scar (*Coding Journal* 2020-2021, p. 57; R Ritchie 2015, pers. comm., 15 September).

This concealing or remaining silent about having breast cancer perpetuates the already low awareness of male breast cancer within the public paradigm. As Rod Ritchie (2019, pers. comm., 27 November, p. 10), explains in his interview that males will not come out with their experience until they feel comfortable. At the moment, men do not feel part of the breast cancer awareness cohort within the broader community context (R Fincher 2016, pers. comm., 14 February, p. 18). Even though breast cancer agencies are becoming more inclusive there is still a long way to go (Ritchie 2019, p. 10). Drawing from my semi-structured interview discussions, I was shocked to find that 44 out of 167 male stories in my research explicitly mentioned that they had no idea that breast cancer existed in men (*Coding Journal* 2020-2021, p. 19). Thomas (2010) further substantiates this finding as 80% of male participants in her research did not know men could get breast cancer.

### 5.2. Medical insight

Currently male breast cancer is increasing, and men have a lower survival rate than women (Cancer Australia, 2021). In turn, I followed up with Rob Fincher (2016, pers. comm., 14 February) who wondered if there was not something medical (or medically motivated) that might increase outcomes for men with breast cancer. Within the medical field, the cause of male breast cancer patient's poorer prognosis, in comparison to females, has two possible explanations: lack of awareness of potential breast cancer in men, or differences in male and female breast cancer biology. This is particularly outlined in Figure 5.1, "Five-year relative survival for breast cancer, 1987-1991 to 2012-2016, by sex" (Cancer Australia 2021) where the graph shows the gap between male and female survival over time and this gap is potentially widening. There is an increase in survival for female patients, but this advantage does not seem to be transferred for male patients (see Figure 5.1).

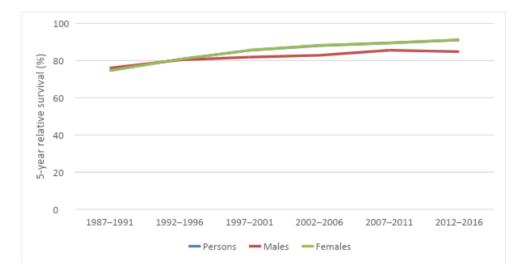


Figure 5.1: Five-year relative survival for breast cancer, 1987–1991 to 2012–2016 Source: (Cancer Australia, 2021)

Whiteside (2017, pers. comm., 17 November) believes that the most probable cause is a lack of awareness, with males presenting later for diagnosis and thus having a later stage cancer. However, Muller et al. (2012, p. 787) found that despite similar stage of diagnoses, male patients had a poorer response to treatment and a lower survival rate than female patients, indicating that it may be biologically different to female breast cancer. As biomarker research which evolves subtle differences between male and female breast cancer biology is being identified. This is further supported by Losurdo et al. (2017, p. 289) who stated, "[I]t is indeed a distinct disease, with its own peculiar biological and clinical features".

From a biological perspective, a male breast cancer patient may be marginalised because male-specific breast cancer is under-researched (NBCF 2016). Cardoso et al. (2018, p. 405), explain how breast cancer is also understood by the medical profession as almost anomalous to a female diagnosis. As Ottini, et al. (2010, p. 142) explain: "[T]o date, there are no published data from prospective randomised trials supporting a specific therapeutic approach in male breast cancer." To extrapolate female treatment for male breast cancer patients may not be optimal; an example is the use of aromatase inhibitors which were designed for female menopausal patients (Ottini et al. 2010, p. 149). Its use in male patients has raised concerns and the use of this endocrine therapy is considered by some oncologists as controversial (Losurdo et al. 2017, p. 287). Wibowo, et al. (2016, p. 784) also allude to the fact that male-specific research is scant, by stating that there are no long-term rigorous studies on the use of tamoxifen in men, even though this drug is a common endocrine treatment which is used for both male and female breast cancer patients.

In considering a gender inclusive perspective for this research, the issue of patients who sit outside the female/male binary is raised. The issue for transgender patients is their birth gender and the effect on awareness which may make diagnosis and awareness of cancer more convoluted. As breast cancer survivor Rod Ritchie (2019, pers. comm., 27 November), explains the LGBTQI community are raising awareness among their community of breast cancer risk regardless of gender. Medical research is inconclusive as to whether sex-organ steroids influence risk of breast cancer, but male to female transgender people were at a higher risk than male patients of getting the disease (de Blok et al. 2019, p. 3). There is also a link between the lack of awareness in male patients and male to female transgender patients. As Dhand et al. (2010, p. 158) exemplify, a transgender patient refused diagnostic testing because she believed being born male protected her against getting breast cancer. While information on transgendered breast cancer patients is small in comparison to the overall patient population, men and transgendered women/men are an invisible component in the branding of breast cancer in pink (J Boyages 2021, pers. comm., 1 March).

The problem of poorer prognosis for male and transgender patients appears to be dual, lack of awareness and the possible different biological profile of male breast cancer. Unfortunately, research into male-specific research does not appear to be on the national agenda. I discovered this from my attendance at the NBCF Community Conversations in Brisbane (November 2013); there was the absence of male patients to voice their concerns. A report was formulated on the direction of research in Australia from the national discussions between NBCF and the public; yet this report does not mention any projected male-specific breast cancer research (NBCF 2017-2018).

As Losurdo et al. (2017, p. 290) explain, "in the best interest of patients, a better global strategy to study male breast cancer prospectively is strongly needed." I could not ignore the fact that male breast cancer was under-researched, and I felt compelled to share the findings of Losurdo et al. (2017) and Muller et al. (2012) with the NBCF, the Australian breast cancer research body by writing to the CEO (see Appendix F2).

I determined, therefore, that the lower survival of male patients was due to lack of awareness, combined with possible biological differences in male and female breast cancer not being addressed in medical research. I set about challenging the efficacy of the current public paradigm of breast cancer awareness for the wellbeing of men (Thomas, 2010) and advocate for male-specific research (Losurdo et al. 2017). I began to create artwork that speaks of the male experience, that challenges the stereotype, and that provides an inclusive model of representation of breast cancer.

# 5.3. Creative works addressing male breast cancer awareness

The aim of my work is to reduce the stigma that some men experience when diagnosed with a stereotypical "women's disease". The artwork that evolved during my doctoral study reflects the degree of invisibility of males with breast cancer. My art practice therefore shines a light on the consequences of gender stereotyping the disease for those other than females and offers alternative strategies to the current paradigm. The artwork that emerged in response to the failings of the current paradigm of awareness are documented as previously mentioned, in an online creative portfolio, the link is: <a href="https://alybaker.myportfolio.com/alyson-baker">https://alybaker.myportfolio.com/alyson-baker</a>. The creative portfolio consists of original artworks produced during my Doctor of Creative Arts research (2018-2021) and is organised by into sections relating to each series of artworks (such as *Illumination* (2021) series) or individual artworks including videos. Each section is labelled to align with the naming of the creative outcomes discussed and exemplified in this chapter. The creative outcomes of this

research are exhibited in the Toowoomba exhibition at USQ Arts Building Foyer Gallery, a Guide to the Artworks and Plan of the exhibition give a broad outline of the artwork and assist in guiding a viewer through the exhibition, these are contained in Appendix M1 and M2. For viewers unable to visit the exhibition an artist statement for the research project is placed at the beginning of the creative outcome section of the digital creative portfolio and each section has an artist statement which briefly describes the context of the artworks. The pivotal impacts of the creative artworks have been the presentation at seminars (in the Research Outcome section of the digital portfolio), entry into USQ video competition Visualise Your Thesis (2021) and publication of *Poster* (2021) in the BCNA Health Professionals Network which will be viewed Australia wide. The exhibition of creative outcomes has been previously exhibited at Karma Collab Hub on the Gold Coast and was attended by Robyn Cameron, NBCF ambassador, and 60 people from the Gold Coast and Brisbane. I have also exhibited some artworks on my Facebook page Breasts and *Chests* which has a following of 164. I have shared the creative outcomes through exhibition and social media in an effort to raise awareness of male breast cancer and provide an inclusive representation of breast cancer.

My creative outcomes are further contextualised and explained in the following Chapter sections (from 5.3 'Creative works addressing male breast cancer awareness' to 5.5 'Agency, advocacy and inclusion'), with each pertaining to the artworks as key findings of this research. Each section refers to the theoretical underpinnings from Chapter Two: Literature Review and artist inspirations gleaned in Chapter Three: Artist Review and how these theoretical underpinnings and artist strategies are translated into the artworks. Some artwork relates directly to the data analysis process while others are a response to the lack of imaging about male breast cancer and the tenet of my practice to provide gender inclusive modalities. Section 5.6 discusses the exhibition of artworks and audience feedback. Finally, I include a short discussion on renaming or reclassifying male breast cancer.

My initial creative response to the lack of awareness of male breast cancer was the making of knitted breasts. I allude to the potential of these knitted breasts to act as a *milagros* to facilitate healing from the individual to the collective (Panicelli 2015, p. 385; Robson & Sumara 2016, p. 636).

#### 5.3.1. Knitting breasts

Within the creative outcome component of this male breast cancer research, I began knitting, which led to making knitted breast forms. Between 2018 and 2021, I knitted 167 breasts. I wanted to represent that number of men who would be diagnosed with breast cancer in Australia in one year (Cancer Australia 2021). Each knitted breast metaphorically represents a man who was diagnosed with breast cancer. I chose the year 2020 as the representative year because I would have current statistical information that was closest to my completion date. In the Knitted Breasts (2018-2021) section of the creative portfolio, I demonstrate the knitting process and the creative outcome of knitted breasts which emerged as a central ongoing, emerging artwork across the duration of my research. The knitted breasts evolved from my arts practice as a breast cancer survivor, after my diagnosis in 2008 the theme of breast cancer began to permeate into my art practice. I knitted breasts as a form of therapy for myself from 2011 to 2013, after I had finished surgical treatment but was receiving endocrine therapy and was processing the trauma of breast cancer. The stitch-by-stitch process of knitting as discussed in the works Ann Hamilton and the humanness of creating knitted artefacts as discussed in the works of Messager in Chapter Three, encouraged my own cathartic experience and sense of mindfulness. The process itself also became a meditative reflection (Schuiling 2014, p. 24), and enabled me to finally come to terms with my own altered body.

The process of knitting was part of my own Autoethnographical exploration. Autoethnography, as discussed in Chapter Four, is concerned with the personal experiences that describe and critique cultural beliefs (Adams et al. 2014, p. 1). By sharing my own experience and that of male stories of breast cancer, in artworks created myself, I describe how men with breast cancer have experienced being a minority in a gender stereotypical disease. As I am outside of the male experience, I took on an ethnographic study, which involved being immersed within the male breast cancer community (Ellis, Adams & Bochner 2010, p. 276) and is later retold through my art practice. I am also cautious to not be telling a story on behalf of others, and therefore employed documentary and interview strategies to ensure that the direct voices of the male breast cancer community are heard. This research then challenges the paradigm, that breast cancer belongs to women, by providing an alternative public awareness paradigm that gives visibility and voice to male patients. In the context of my knitted breasts, they allude not only to my experience of breast cancer (my *insider* status), but also to the experience of the men in my research (my *outsider* research status). I knitted 167 breasts; the number 167 is also the number of stories analysed and recorded in the *Coding Journal* (2020-2021). The auto/ethnographical approach in this research systematically describes and analyses (Ellis, Adams & Bochner 2010, p. 273) my personal experience through the process of knitting and links it to the male experience with the metaphorical images of knitted breasts.

The first knitted breast form that I made in 2011 happened by accident. The knitted work ended up being unravelled and mishappen, although I immediately identified the form as resembling a breast; as well as its very "unplanned" and "messy" process metaphorically spoke volumes about my own as well as the more collective breast cancer experience. I had no pattern; I started to randomly knit as a means of finding my way through the labyrinth of medical information and the trauma of having breast cancer. Interestingly, the triangular or geometric approach to the representational breast form surpasses gender specificity, that is, beyond a binary context. In other words, the forms are not concerned with evoking a life-like male or a female breast by rather have a symbolic form that takes on non-binary resonance of breast cancer issues with inclusive, collective purpose to raise awareness.

From an Autoethnographical and deeply personal level, my initial knitted breast (see Figure 5.2 (a) evokes my own altered state both physically and emotionally, as I felt "unravelled". The certainty and reliability of my life had fallen apart; I wondered if I would survive. Losing a breast was one of my fears, death was the other, I was undergoing reconstruction straight after my mastectomy and I felt like a "work in progress". The act of knitting and its tactile process grounded me and became my guiding light; it helped me feel like I could cope. After about five years I felt, I had come to terms with my altered body and my experience; it was then that I expanded my practice by creating artwork to express other people's experiences of breast cancer. I knitted breasts in merino wool as it is a quality and organic material, I wanted to create images that showed a respect and honoured the people I was representing. I developed my own breast pattern with a casting off in a spiral and this became the mainstay process for the knitted breasts in this research (see Figure 5.2 (b)).

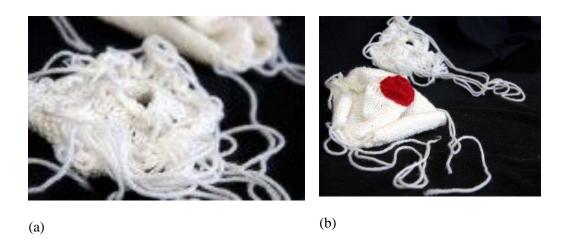


Figure 5.2: Alyson Baker Knitted Breasts (cited in Trial to Triumph 2011)

In 2018, I started knitting breasts again, as Rod Ritchie (2019, pers. comm., 27 November, p. 10) explained approximately 150 men are diagnosed with breast cancer in Australia in one year. Over the research period, I found that the actual number was higher than that; the NBCF estimated that the amount of diagnosis of males was 167 in 2020 (NBCF, 2021). The knitted breasts are metaphorical images, each represents a man with breast cancer, these breasts are the artistic link between the male experience and my own. By using a slow mediative arts practice and by ghosting the stories of male breast cancer in each stitch, in each knitted breast, a collection of knitted breasts emerged (See Figure 5.3). The knitted breast pattern was altered to form a nipple-less breast; to represent that most men are diagnosed at a later stage and need a mastectomy (Cruz et al. 2019, p. 3943). They are textile sculptures that allude to the fact that male breast cancer commonly presents as a mass or nipple abnormality such as retraction, ulceration, discharge, and bleeding (Giordano et al. 2020, p. 682). The knitted breasts `manifest the number of men with breast cancer in 2020 in a physical, tactile form.

I chose to translate each story that I read in the research period, into a knitted breast and the collective into the artwork *Standard* (2018-2021) which is represented in Figure 5.4. Historically a "standard" was a war flag, a variation of a country's flag used by military forces (Marine Corps Gazette 1972, p. 6). The meaning of standard

in the context of my artwork is two-fold, the flag as a "standard" to follow into battle, this reflects the clique of "battling" cancer; while the concept "standard" also references the statistics contained within the artwork. The *Standard* artwork (2018-2021) is composed of 167 individual knitted breasts which have been placed together to create the form of a battle "standard". In this way, the *Standard* (2018-2021) reflects the individual and collective experience of male breast cancer. The hope is that these knitted breasts may also act as a *milagros* as addressed in the work of Janine Antoni in Chapter Three to create healing from the individual to the collective (Robson & Sumara 2016, p. 636). This healing is most likely to occur by increasing the visibility of male breast cancer to increase awareness.

The documentation for the rationale of knitting process, materials, and analysis of these textile sculptures are contained in my *Artist Journals* (2018-2020 and 2021). It was through the process of knitting and calligraphy that I was able to analyse the male experience of breast cancer. During the DCA period from mid-2018 to mid-2021, I continued knitting breasts and documenting my research in calligraphy. The result was 167 knitted breasts, to represent the number of men diagnosed with breast cancer in one year, specifically 2020, these were laid in a *Standard (Artist Journal* 2021, p. 40) and four books: *Artist Journal* (2018-2020) and *Artist Journal* (2020-2021) are where I recorded my reflections, ideas for creative work and the medical information I researched about breast cancer. *Artist Journal* (2021) documents my analysis of the representational text manifested during this DCA while the *Coding Journal* (2020-2021) is the Grounded Theory coding of video transcripts and written stories by male breast cancer patients.



Figure 5.3: Alyson Baker 167 Knitted Breasts (2018-2021)

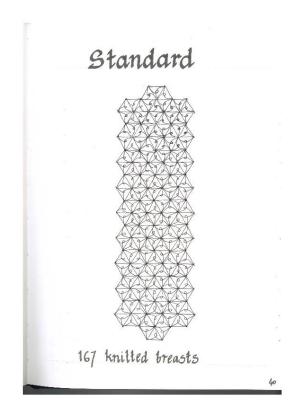


Figure 5.4: Alyson Baker *Design for Standard* (2018-2021) Source: Alyson Baker *Artist Journal* (2021, p. 40)

#### 5.3.2. Artistically rendered coding

I documented the process of coding and analysing my data sets, the written stories and video transcripts from men with breast cancer, in calligraphy. I chose calligraphy because like knitting it allowed a slow meditative practice, I could reflect on the words and phrases and the documentation of my research. Calligraphy was my choice of modality to document my Honours research (2015-2016), it was also the time when my husband was dying from cancer. I continued this practice of calligraphy as it helped me to be mindful and was my therapy during this DCA as I also lost my father in late 2018. So, the process of documentation in calligraphy in this DCA stemmed from my own therapeutic art practice. The slow process of writing grounded me and allowed me to consider the gravity of the stories I read as I created a reflexive practice. As Charmaz's (2008, p. 163) guidelines suggest, by engaging in reflexivity it can challenge the researcher's preconceived ideas or assumptions. For me, it was through my research that I was able to innovate the concept of *Illumination*, I could consider gender as being on a continuum rather than a dichotomy and I could translate my data analysis into artwork, thus developing my own arts practice.

The Coding Journal (2020-2021) documents the theoretical categories in this research, supported by quotations that were induced from the coding system. It was also a way of systematically manifesting a discursive translation of the stories into codes through the artistic modality of calligraphy. My research discovery was that by making the data analysis into a calligraphy book, it became an artwork that made transparent the analytical choices of the researcher (Charmaz 2008, p. 162). As Charmaz (2008, p. 162) describes, in constructivist Grounded Theory the "researcher can see and create a direct relationship between data and abstract categories". Grounded Theory from a constructivist perspective allows for abduction, the intuitive interpretation of observations and allows for creative ideas that may account for these (Charmaz, 2017). Surprisingly though, Charmaz (2008) does not elaborate on the use of the analytical process to create works of art. This is where I feel I have contributed to art-based practice, by allowing the research process to be transparent and embedded in the artwork. As a visual artist, I actually rendered the coding process into artwork as I understood that my art-based research would manifest in a visual modality. This is my contribution to arts-based research where calligraphy is

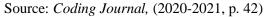
both a coding process and an artwork. As Charmaz (2008, p. 160) explains "The method does not stand outside the research process, it resides within it". The *Coding Journal* (2020-2021) contains the theoretical categories with didactics to describe each category (see Figure 5.5). I also created visual motifs for each theoretical category, which are the visual descriptions (See Figure 5.6) of each category.

us mul

breast cancer is a "woman's disease"

Figure 5.5: Alyson Baker Theoretical Category Stereotype,

42



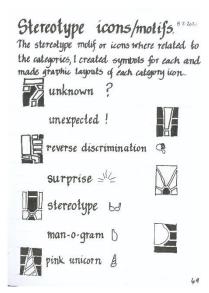


Figure 5.6: Alyson Baker Theoretical Categories Visual Motifs Source: *Artist Journal*, (2020-2021, p. 49)

The above two creative modalities of calligraphy and knitting manifest visual data representations that pronounce the lack of knowledge about male breast cancer,

became the mainstay of my own artistic practice. They are intensely physical modalities and translate empirical data (the number of men diagnosed with the disease in 2020) and the data analysis directly into artworks. By documenting my research and coding as rendered knitting and calligraphy, I literally increased the visibility of male breast cancer through the artwork that emerged and grew throughout the entire research period. The theoretical categories that emerged during my data analysis are represented in the *Illumination* series (2021) with the evidence of each category in the *Stereotype and Flong* series (2021).

# 5.4. The emergent artmaking process through data analysis

The *Illumination* (2021) and the *Stereotype and Flong* (2021) series, are artworks that emerged from the data analysis of this research and can be viewed in the creative portfolio. I used video recording transcripts and written stories from the MBCC (2021) website, which are stories by male breast cancer patients, as my data sets for analysis. As Robson and Sumara (2016, p. 617) explain the inclusion of participants' own creative work has the potential for a project to create social change from an individual level to the broader community. The underlining strategy was to collect 167 Autoethnographical representations, written stories or video recordings where men share their breast cancer story, thus allowing the men to tell their experiences on their terms. This approach aligns with the contestation of breast cancer as a female disease and so self-disclosure can assist men to reclaim their sense of masculinity (Donovan & Flynn 2007, p. 464). It was a deliberate and unique strategy to insert their voices in the body of works as male breast cancer is currently underrepresented (Thomas 2010, p. 34).

During the data analysis (June 2020-June 2021) section of the Post-Confirmation Phase described in Table 4.2, I found the analytical elements of the coding process of Grounded Theory, the theoretical categories and supporting evidence for each category. As American artist, Ann Hamilton (cited in Wallach, 2008, p. 54), explains, "words are a *material*" *and* verbatim text can be used to form an artwork. In *CHORUS* (2018) Hamilton used words carved in marble, which was chosen to replicate monuments, that gave the words a sense of memorial and the words themselves were the material for the artwork (Hamilton 2018). In this research, the category names and supporting quotations of my data analysis, the words are the material that I manifest into artworks. Although I began by knitting breasts and documenting my findings in calligraphy in the *Art Journals* (2018-2020; 2020-2021), as discussed in section 5.3.2, I extended my arts practice through expanding my research methodology by translating my data analysis into other modalities.

Grounded Theory is an expressly emergent methodology (Charmaz 2008, p. 155). By using the coding guidelines, it allowed me to check and code data as the project progressed. In this way, the data analysis provided inspiration for the creation of new artworks directly in response to the data coding. It was by engaging in the coding guidelines that new knowledge emerged, particularly as I did not initially understand the extent of marginalisation experienced and expressed by male breast cancer patients. I started collating quotations from the stories I read, and commonalities began to arise. As discussed in Chapter Four, as I analysed 167 male breast cancer stories; eight theoretical categories emerged from this narrative material. I named the theoretical categories as: Unknown, Unexpected, Stereotype, Reverse Discrimination, Surprise, Manogram, Pink Unicorn, and Secret. To validate whether these categories were organic and the most effective representation of the phenomena, I conducted a further focused reading to colour code the sections of the stories where the theoretical category appeared (See Post-Confirmation Phase June 2020 – June 2021). I wrote quotations, verbatim text, from the stories in each category using calligraphy in the Coding Journal (2020-2021). The quotations became evidence of the theoretical category and some of the quotations became the materials for further artworks: *Illumination* (2021) and *Stereotype and Flong* (2021) series. Detailed descriptions and illustrations of this process are contained in the Methodology Chapter Section 4.5.1

To describe the theoretical categories, I used discursive text, dictionary descriptions or direct quotations from my data sets (*Coding Journal* 2020-2021, pp. 1, 11, 20, 30, 42, 49, 41, 55). I also rendered this text into presentational text, featuring visual motifs to describe each theoretical category (see Figure 5.7 and *Artist Journal* 2020-2021 in my online creative portfolio). These visual descriptions of the theoretical categories are my artistic response to the types of detailed coding I

undertook through applying Grounded Theory methodology. What I discovered was that translating the theoretical categories into the *Illumination* (2021) and *Stereotype and Flong* series (2021) allowed for the direct translation of data analysis to be transparent. It was through the articulation of the coding into artworks that the audience in my exhibitions could participate in the interactive process of *Illumination*. It was in translating the data into a modality named "stereotype" that I could interweave the concept and consequence of breast cancer as a gender stereotype.

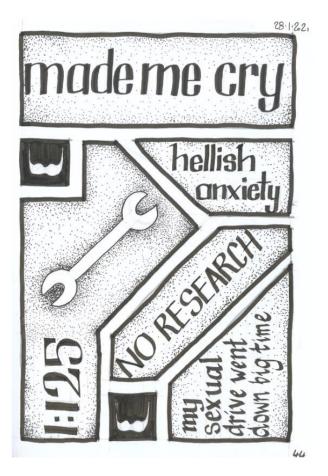


Figure 5.7: Detailed Coding example: *Unknown* Source: Alyson Baker *Artist Journal* (2020-2021, p. 44)

My coding process revealed common incidents (Charmaz 2008, p. 164), and, as Charmaz (2008) explains, the codes explain the conditions under which the category occurs. For example, in the category *Unexpected* the commonly recurring trope was that the male patients explicitly mentioned that they did not know breast cancer existed in men (*Coding Journal* 2020-2021, p. 19). Using colour-coding to further shape the categories, I highlighted the written stories and transcripts to find

quotations that fitted each category. I then collated the quotations under each category heading into the Coding Journal (2020-2021). As a researcher, I could choose the artistic methods and create them as my inquiry emerged (Charmaz 2008, p. 162). This allowed for not only the transparency of the coding methodology but also the transference of the theoretical categories and supporting quotations into artworks. The analytical choices of Grounded Theory coding and the link between the artmaking become transparent by manifesting the theoretical category names and the verbatim quotations into the artworks *Illumination* (2021) and *Stereotype* (2021) which were exhibited side by side (exhibition at Karma Collab Hub, 16 October 2021). I observed the audience using the torches to illuminate the theoretical category names and I observed people reading the stereotypes in conjunction with the illumination drawings. I manifested a direct relationship between the data sets and the theoretical categories (Charmaz, 2008, p. 162) in visual storytelling. The Illumination (2021) series, therefore, directly transfers the theoretical categories into artwork and is my contribution to the arts field. However, it was the engagement by viewers of the artworks and their feedback both orally and in writing (see Appendix G1) that affirmed that the exhibition gave visibility and voice to male breast cancer patients.

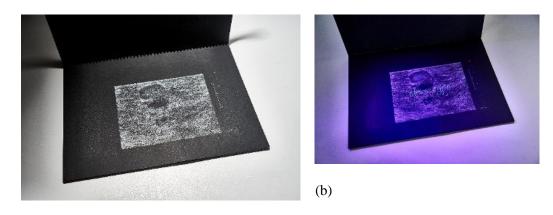
#### 5.4.1. Illumination (2021) Series

To make the *Illumination* (2021) series, that emerged in the Post-Confirmation Phase (June 2020 – June 2021), I used an *illumination* concept to document the category names and represented each in a palimpsest (Refer Figure 5.10 and *Illumination* (2021) series in my online creative portfolio). To make the palimpsest, all of the category names: *Unknown, Unexpected, Surprise, Reverse Discrimination, Stereotype, Manogram, Pink Unicorn* and *Secret,* were hidden by writing the names in invisible ink calligraphy. Images of Rod Ritchie's (2021) tumour were drawn over the top of the text in watercolour pencil to replicate a visual similarity to an ultrasound (Refer Appendix J).

I deliberately chose the term *illumination*; it is a reversal of the concept of *erasure*. *Erasure* is where elements of the artwork are removed to create emotive reactions, to represent loss; this was exemplified in Dan Elborne's *One Drop of Blood* 2013 (see Section 3.5.5). *Illumination* is an antithesis to erasure in that it relies

on the addition of light to provide a deeper insight to the artwork. *Illumination* is a participatory medium where the viewer shines a light, literally, to discover how men feel having a stereotypical women's disease. I chose to write the category headings in invisible ink to reflect the "silence and invisibility" that Audrey Lourdes (cited in Price Herndl 2006, p. 221) expressed in her *Cancer Journals* (1980). Although Lourdes (cited in Price Herndl 2006, p. 221) refers to women with breast cancer, by not wearing a prosthetic breast she critiqued the concealment of breast cancer. It was by the "outing" of women's images with breast cancer that for women, that today there is no stigma associated for a woman with breast cancer (Peterson & Matuschka, 2004, p. 510).

Men, however, conceal their mastectomy scars as they are often embarrassed to be associated with what is stereotypically a woman's disease. The *Illumination* (2021) series serves to counter the stereotypical representation of breast cancer as belonging to women by shining a light on the responses of men with breast cancer. The *Illumination* (2021) series is an interactive artwork (see Figure 5.8 a & b and my online creative portfolio). As men are reluctant to "come out" with their experience (Ritchie 2019, p. 10), I engaged, to a large extent in a type of covert research, by analysing published stories to glean the male experience and their feelings. The *Illumination* (2021) drawings allude to the invisibility of images and stories about male breast cancer in the current awareness paradigm. From the outset the viewer sees the ultrasound (see Figure 5.8 (a)), it is only through the process of shining a black light on the drawing that the theoretical category may be discovered (see Figure 5.8 (b)); in this way the audience become researchers themselves, searching for evidence of marginalisation.



(a)



The modality of invisible ink and drawing to make the palimpsest in the *Illumination* (2021) series was induced from my experimentation of calligraphy and mammogram drawing (see Figure 5.9). I was responding to the story by Khevin Barnes (MBCC, 2016) where he asked for a renaming of some procedures to sound more masculine.

I wonder sometimes if a simple name change of the medical procedures might help men to talk more openly about their bodies. I'm thinking that a "man-o-gram" might convince more guys to have their breasts checked, especially the over 60 group like me, statistically found to be most likely to contract the disease. Khevin Barnes (*Coding Journal*, 2020-2021, p. 50).



Figure 5.9: Alyson Baker Manogram Calligraphy Drawing (2020)

However, after consultation with Prof John Boyages, he recommended that an ultrasound would be less invasive diagnostic imaging for men. Rod Ritchie kindly donated his ultrasound images for the Illumination (2021) series (see Appendix J). The inspiration for using invisible ink in the *Illumination* (2021) series came from the male breast cancer patients' responses, to conceal their diagnosis. Some stories explain how men did not seek psychological help for their trauma or covered up their chest, so they did not have to explain about having breast cancer. Some said that they were embarrassed and had experienced a sense of private body shame. 21 of the 167 (12.5%) men in my research mentioned that they cover their scars in public due to body shame. Lee Simmons (cited in MBCC, 2016) explained that he was diagnosed and given a mastectomy during the Vietnam war, for years after he explained that his scar was a war wound. In stark contrast to Lorde (1980), Matuschka (1993) and Spence (1982-1984), female artists, who came out with their experience of breast cancer to raise awareness and advocate for better treatment for women, as far as I know there are only a few male artists with breast cancer representing their own experience (these are on the MBCC website), as men tend to remain silent and

invisible. Section 3.2 describes how the "coming out" of women with breast cancer has meant that the disease is devoid of stigma for women (Peterson & Matuschka, 2004, p. 510). Men's reluctance to share their experience perpetuates the notion that breast cancer is a "women's disease" and limits awareness raising (J Boyages 2021, pers. comm., 1 March; *Coding Journal* p. 43). There is also a correlation between men's lack of visibility in images and stories represented in the public media that also reasonably perpetuates the notion that breast cancer belongs only to women.

#### 5.4.2. Stereotypes and Flongs (2021) Series

My initial strategy in response to the lack of visibility of men with breast cancer was to find out how it was manifested in society (McRuer 2006, p. 2) by highlighting the consequences for men with breast cancer. Once the eight theoretical categories emerged, along with my collation of the quotations as evidence, I made tables of frequency as empirical data to be used in publications for conference papers and future journal articles (*Coding Journal* 2020-2021, pp. 19, 48, 50, 52; *Artist Journal* 2020-2021, p. 41, 58). Quotations, evidence for theoretical categories, also became a material (Hamilton & McHale 2020, p. 227) for incorporation into my artwork entitled *Stereotype and Flongs* (2021) series; one example is shown in Figure 5.10 (refer to my online creative portfolio for the whole series). I manifested the data analysis into representational text by embossing some of the quotes from my *Coding Journal* (2020-2021) in calligraphy on copper sheets and fashioned a paper mould by printing and embossing on paper. I chose this method to replicate a "stereotype", a now disused print making technique (Melbourne Museum of Printing 2007, p. 429).

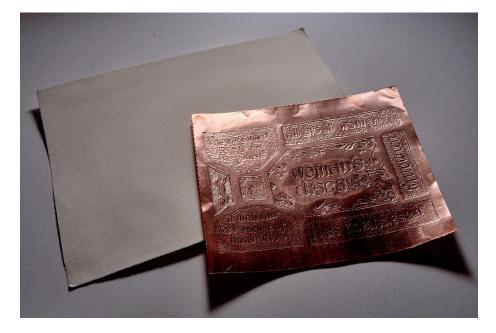


Figure 5.10: Alyson Baker Stereotype and Flong Stereotype (2021)

Traditionally the stereotype was a cast copper plate made from a "flong". The "flong", was a paper mould taken from text and images in metal that were laid out in panels, when molten copper was poured into the mould it made an onomatopoeic sound "clique". In this research some of the artwork relates to the cliques associated with breast cancer, for example 20 out of 167 men in my research referred to breast cancer as a "woman's disease" (*Coding Journal* 2020-2021, p. 48). This clique of breast cancer as a "woman's disease" is perpetuated by the pink colour, the gender colour stereotyping used to market the disease (J Boyages 2021, pers. comm., 1 March). The stereotype in this research is paradoxical, it is a literal printmaking modality, but it is used to reveal that the stereotype of breast cancer as a "woman's disease" is flawed and prone to *erasing* male patients. I used traditional materials – copper for the stereotype plate and paper for the "flong". I embossed some of the text from the *Coding Journal* (2020-2021) in a similar font to the calligraphy in the journal. I then created a "flong" by printing on paper from the copper embossed stereotype (See Figure 5.10).

I included the "flong" as it replicated the mould of the stereotype, and in the case of this research, it is the entrenchment of gender stereotyping through the Pink Ribbon Campaign (Koller 2008, p. 395). I counter the reference of breast cancer as a "women's disease", this clique is often associated with the disease and the

implication is that the use of pink to market breast cancer perpetuates this notion (R Fincher 2016, pers. comm., 14 February p. 6; J Boyages 2021, pers. comm., 1 March). By embossing the quotations into the stereotype plate, I etched male feelings of having a stereotypical women's disease by documenting authentic responses. It was a strategic move to show the authentic experiences of men with breast cancer in the form of a stereotype and its associated mould – the "flong". The embossed copper sheet is the "stereotype plate" while the "flong" replicates the traditional mould. I alluded to the gender stereotyping of breast cancer by using the modality called "stereotype" and the embossing documents the male experiences. It is etched in the plate to allude to the entrenchment of the current paradigm of awareness and its consequences for men. Some quotations were in larger calligraphy to give importance or monumentality (Curnow 2016, p. 210). In the calligraphy, I have surrounded some panels with visual motifs and calligraphy scrolls, flourished lines, which are embossed in the stereotypes so that the viewer's gaze is focused on these texts giving them significance (Hamilton & McHale 2020, p. 226). I included motifs from my pre-study work, bras and spanners, to allude to the "misfit" of male breast cancer in the current paradigm of awareness.

McRuer's (2006) Crip Theory aims to destabilise dominant assumptions that are taken for granted in our society (Goodley and Runswick-Cole 2016, p.1). As McRuer explains, a researcher must first understand why and how an assumption is embedded in society so that it may be destabilised (McRuer 2006, p. 2). Richardson (2016, p. 177) explains that showing images of people who are different from the normative is an inclusive strategy, he does however, caution that people are not aggrandised or "enfreaked". I began exploring ways to increase the visibility of male bodies with breast cancer, to destabilise dominant assumption that breast cancer belongs to women, and to advocate for better conditions for men. I also linked my own story with that of the males as a precursor to an inclusive representation of breast cancer so that men belong in the dialogue and imaging of breast cancer. The aim was to give agency to the male patients, to advocate for them and provide inclusive models of representation of people with breast cancer.

The contributions that I have made in this research is through the manifestation of the concept of *illumination* and how this also helped to illuminate my model of practice. This has specifically emerged as my translation of my actual data analysis through theoretical coding and sampling into artworks. It was through experimenting with mammogram drawing and calligraphy that the concept of illumination emerged and afforded me the ability to link the reluctance of men to share their breast cancer experience that induced the idea of using invisible ink. It was the notion that ultrasounds are less invasive and a good first point for investigation (J Boyages 2021, pers. comm., 1 March) that induced the unlit images in the *Illumination* (2021) series. The invisibility of male bodies with breast cancer validated the use of invisible ink to record the theoretical categories that allude to male marginalisation.

The *Stereotype and Flong* (2021) series, is about documenting the evidence of the marginalisation of men with breast cancer using direct quotations. The stories that I read kept seeping into the artwork through the verbatim text that was amalgamated into the artworks. It was the coding method that dictated the verbatim text to be embossed in the artwork. By framing together these artworks as a direct correlation between the category and its supporting evidence, I manifested what Charmaz may never have imagined. By using this participatory modality, shining a light to discover the marginalisation of men, the audience might more effectively invest time in the artworks and reconsider their own understanding of breast cancer. In Chapter Two: Literature Review I discovered and discussed how the paradigm of breast cancer was entrenched in society; this directly influenced how I sought to illuminate the way that the paradigm is entrenched and thus set up a premise for sharing the consequences for men with breast cancer. Once I understood how men felt having a stereotypical women's disease, I could set about offering alternative strategies through my arts practice to advocate for men with breast cancer.

My arts practice uses diverse modalities, each aptly expresses the concepts that I wish to communicate. The creative outcomes of this research are documented in my digital creative portfolio and may be viewed online. The creative portfolio contains images of all the artwork that was exhibited at the exhibition at Karma Collab Hub in Miami, Gold Coast, on 16 October 2021 and at USQ in December 2021 and January 2022 <a href="https://alybaker.myportfolio.com/alyson-baker">https://alybaker.myportfolio.com/alyson-baker</a>. As a creative outcome, the exhibition gave visibility and voice to the male patients. I also received feedback that the exhibition was inclusive of the diversity of patients affected by breast cancer (See

Appendix G1) and as such I had achieved some aims of my research and addressed the research question.

I also advocated for male breast cancer to increase awareness by attending conferences, writing to breast cancer agencies, entering the USQ *Visualise Your Thesis* video competition, organising exhibitions of my artwork, and distributing the educational *Poster* (2021) to share the findings of my research. I also shared some of the creative works on my Facebook page *Breasts and Chests* which has a following of 164. One pivotal finding was that the video for the *Visualise Your Thesis* (2021) competition was a succinct way to share my research and became the catalyst for an invitation to exhibit the artworks at USQ's new art gallery in 2023. Another was that *Poster* (2021) was received by BCNA and they asked if they could publish on their Health Professionals Network, as an Australian health resource (See Appendix F4).

### 5.5. Agency, advocacy and inclusion

The continual challenge I faced with this research was the lack of males willing to share their experience. This was also noted by Rod Ritchie (2019) during my interview with him, he said,

> Of the 150 men in Australia each year diagnosed, I might meet 1 or 2 or them, and I am on all the public blogs that deal with breast cancer. There is a move for some breast cancer charities to be inclusive of the men now, but these men are still being diagnosed, still being treated, but they are not coming out. I feel they won't come out until they feel comfortable. Who would? It is a bit like gender inequality, we need to feel like we are part of the cohort, we need to feel like we are going to be accepted as men with the disease, and not put in a corner, or whispered about. We need to belong to the breast cancer community. (Ritchie 2019, p.10)

The main obstacle for men "coming out" with their experience of breast cancer is that a diagnosis of breast cancer contests masculinity (J Boyages 2021, pers. comm., 1 March). The evidence, tallying direct quotations, induced that 43 out of 167 (26%) of men in my research mentioned that breast cancer is a "woman's disease" or commented on the gender bias in the representation of the disease (*Coding Journal* 2020-2021, p. 48). A man is confronted with the "pink" of breast cancer (R Fincher 2016, pers. comm., 14 February p. 18).

To position the artworks as having agency, I used verbatim text from the male stories provided on the MBCC website (discussed in Section 5.4). I also recorded similar male feelings or responses, from tallying similar quotations, and recorded this as empirical evidence in tables and statistics in my *Coding Journal* (2020-2021). The rationale for using verbatim text was to collate genuine artefacts, text as a material, for amalgamation into artworks (Hamilton 2018). As Sheikh (2008, p. 85) explains, writing about traumatic experiences is a way of coming to terms with the experience, although I have never met the men from the MBCC website, they were willing to retell their trauma, which enabled me to act on their behalf. Through the MBCC, men felt safe to relate their experiences, and I acted as a translator of their stories. My artwork is a manifestation of their emotional responses to being a minority. The artistic responses counter the clinical and didactic information that is usually found in doctors' offices; the artworks aim to provide authentic representations of breast cancer patients' experiences. The artwork is intended, first and foremost, to acknowledge the stories of the unknown and known participants of this research.

At the start of this DCA project, I had a suspicion that men were marginalised, but I was shocked to find the extent of marginalisation that men with breast cancer experienced. Through the slow yet meditative process of reading, coding and recording in calligraphy, I had time to reflect on the male experiences. I found that eight men mentioned stigma in health care settings as they were "set up" for women: while a further 24 men specifically voiced their concerns that treatment was based on female studies or images and literature was female oriented (*Coding Journal* 2020-2021, p. 48). They stated that during interactions at health care facilities sometimes the staff did not even know that men could get breast cancer (Herbert, *Coding Journal* 2020-2021, p. 45). The discrimination some men articulated extended from the lack of knowledge about males with breast cancer (Goldstein, *Coding Journal* 2020-2021, p. 35), some patients could only fill out their name on medical forms as all other information was related to female gynaecology (Gardo, *Coding Journal* 2020-2021, p. 33), and in some cases, they were treated with disrespect due to being

male (Michael C, *Coding Journal* 2020-2021, p. 31). In Australia, men do not qualify for medical rebates for diagnostic imaging (R Ritchie 2019, pers. comm., 27 November, p. 10) and in some countries, men do not qualify for insurance because of their gender (Carr, *Coding Journal* 2020-2021, p. 32). It was through my analysis of the data sets that I noticed the *othering* of male patients in health care settings, this was confirmed by Midding et al. (2018, p. 2203) who stated that the highest level of *othering* for men with breast cancer came from health care settings. Men felt excluded as the medical facilities where they were required to attend were often given female names such as "Women's Hospital" (Miller, cited in MBCC 2016). The Women's Imaging Centre where I have my own annual surveillance does include males, but they must be taken through a different entrance and do not sit with female patients. My response to the othering of men in health care facilities was to write to the Women's Imaging Centre and asked that they would consider renaming the facility to be gender inclusive and display my educational poster to raise awareness of male breast cancer (See Appendix F1).

#### 5.5.1. Advocacy letters

I also read 12 direct references by men that they were concerned that information about breast cancer and treatment was based only on women's studies (*Coding Journal* 2020-2021, p. 48). As a multidisciplinary artist, I explored multiple ways to articulate an idea or concept as I wanted to inform the breast cancer agencies of my findings and advocate for males with breast cancer (See Appendices F 2 and F3). The commonly accepted form of information transfer to the breast cancer agencies is via their public liaison personnel. I fashioned a letter as this is the usual approach to these agencies, with the aim of relaying my findings in a modality that they were acquainted with. The notion that male-specific research is needed, induced in the previous section of this chapter, was verified by Rob Fincher (2016, pers. comm., 14 February) when he said, "Let's get serious we are all part of the same health issue". In 2016, the NBCF noted that male-specific research is lacking:

The rarity has resulted in a lack of male breast cancer specific national or international research and as a result, little is still known about male breast cancer with all treatment taken from knowledge attained from female breast cancer studies, which is not ideal. (nbcf.org.au, 2016)

It is indeed a time to get serious and my letter to the NBCF was written in response to, by their own admission, the lack of male medical research (see Appendix F2). BCNA, the national body for advocacy for breast cancer patients, have included reports on how to best support men with breast cancer and have advocated for better conditions in health care settings for men. To further the awareness of men with breast cancer, I also sent a letter to their liaison personnel and included an information poster for publication in their newsletters and on their website (see Appendices F 3 and F4).

#### 5.5.2. Poster

The overarching reasons why men felt discriminated against in health care settings was that sometimes staff were unaware that male patients may present to the clinics, the décor and naming was also female biased. I decided to create an educational poster to put in doctor's offices, donate to NBCF and BCNA for educational purposes, to upload onto my Facebook page, website and for public exhibition. The inspiration came from reading a story by Roger Grates (2016) where he describes how his breast cancer was found:

> At the surgeon's office, I had left my reading material in the waiting room.... Out of sheer boredom I read the breast cancer poster on the wall. One of the symptoms mentioned was an inverted nipple, which I had for two or three years. When I brought this to the doctor's attention, he felt the lump in the nipple areas and decided it should be removed. (Roger Grates cited in MBCC, 2016)

The *Poster* (2021) was created in collaboration with Prof. John Boyages AM, internationally recognised radiation oncologist, breast cancer specialist and author of *Male Breast Cancer: Taking Control*, and Tenielle Grace, graphic artist. We made an educational poster to raise awareness of male breast cancer and make suggestions on what to do if someone notices any changes in their breast. I coined the slogan "[A]nybody can get breast cancer" to reference that breast cancer can affect anybody regardless of gender, the use of the male image also alludes to the male image as being a transgressive "body" (Richardson 2016, p.172). Professor Boyages, AM (2021, pers. comm., 1 March) felt that having a male image would shake up the common perception of the disease as belonging only to women. He also gave

suggestions on the text which would inform readers of symptoms of breast cancer and what to do if they noticed any breast changes. To avoid aggrandising or the "enfreakment" (Richardson 2016, p. 177) of Rod Ritchie whose photograph I took in 2015, and was used for Poster (2021), I involved him in the review process (see Appendix E). The layout, fonts and colours were designed by Teneille Grace. I approached her to work collaboratively on the design of the poster; she offered her services pro-bono as she is a breast cancer survivor and felt this project was important. In consultation with her she suggested that the copyright be assigned to me, to provide ease of distribution particularly in the future. My breast surgeon and general practitioner, on hearing that I had created an information poster, asked if they could put it up in their waiting rooms (See Figure 5.11).

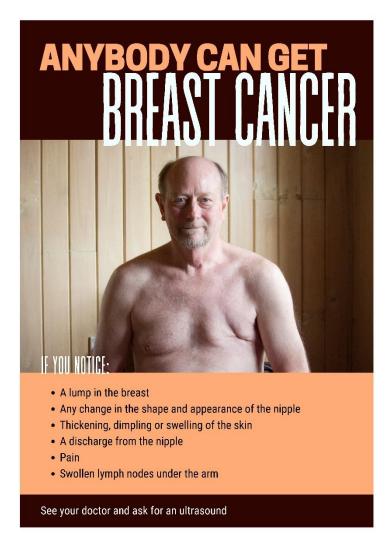


Figure 5.11: Alyson Baker in collaboration with Prof. John Boyages

and Teneille Grace, Poster (2021)

### 5.5.3. Agency for men and women in watercolour painting and video

As a response to the exclusion of men in the depiction of breast cancer I was inspired by Cecil Herrin's (*Coding Journal* 2020-2021, p. 46) suggestion where he explains,

[A]ll the images out there about breast cancer shouldn't be just of women. Have a man standing side by side with a woman in the pictures. We need the exposure.

The creative works that emerged from this simple comment, became the catalyst to include female images and stories with the male stories I was collecting. I revisited my pre-study documentation videos where I had compiled a video of men and women with breast cancer which had never been published. This video *Conversations* (2015-2016) was made in an effort to reveal the gravity of the disease: from diagnosis, reaction to treatment, terminal diagnosis, and the possible future for finding a cure for breast cancer (*Conversations*, 2015-2016 in online creative portfolio). I was staggered when I put together the male and female stories how the emotional issues crossed gender boundaries. In the stories of men with breast cancer and the video transcripts from male and female patients they shared some commonality. While not an exhaustive sample, both men and women in this video resented the branding of breast cancer in the colour pink, as it sanitised the trauma and gravity of the disease (R Fincher 2016, pers. comm, 14 February). Both men and women felt a loss of gender identity due to their treatment for breast cancer (McDermid, 2016, p. 23; Fincher, 2016, p. 16).

Both men and women faced body issues related to mastectomy and their experience of an altered body (Excell, 2016, p. 23; Troyer in *Coding Journal*, 2020-2021, p. 48). This evidence added weight to my hunch that breast cancer needed to be represented as inclusive of all genders. This knowledge underpinned the decision to create watercolour paintings of *Rob* (2020), *Karlee and Eli* (2020) and *Sword Fighter* (2020) shown in Figure 5.12; all of the watercolour paintings are in the online creative portfolio. The rationale to exhibit these watercolour paintings together was also a response to Cecil Herrin's desire to have men and women standing side by side. This decision also affirmed what I had felt, that by excluding the female images in my depiction of breast cancer I would create a male gender bias. As my arts practice aims for inclusiveness, the female participants from my Honours research (2015-2016) were included in accordance with Ethical Review H19REA060 (v2).



Figure 5.12: Alyson Baker Sword Fighter 2020

#### 5.5.4. Manogram video

As the research is a combination of Autoethnography and Grounded Theory, I decided to link my experience of being a female with breast cancer to the male experience through my art practice of knitting breasts, video recording and reading stories about breast cancer. In *Manogram* (2020), I used the verbatim audio from video interviews so that the principal participants' viewpoints were told authentically (see video still in Figure 5.13, full video in my online creative portfolio). The process of gathering the principal participant's Autoethnographical representations, including video interviews and written stories all become observations of male breast cancer (Ellis, Adams & Bochner 2010, p. 276).

In this research I used the verbatim oral text as a material, I used written quotations gleaned from my data analysis in my stereotypes. Using the emergent process of coding the video transcripts I found that some verbatim oral text had the same theoretical categories as my written data analysis (Charmaz 2008, p. 164). I amalgamated my experience, through the process of knitting breasts, with the verbatim audio, oral text, from the video recordings of Rob Fincher (2016, pers. comm., 14 February) and Rod Ritchie (2019, pers. comm., 27 November). By amalgamating my own story with theirs, I juxtaposed (Hamilton cited in Johnson, 2020, p. 2) the male and female experience to create an inclusive model of breast cancer. The word "manogram" which was laid out in yarn refers to the renaming of breast cancer and some procedures to sound more masculine (*Coding Journal*, 2020-2021, p.49). I read the word "manogram" in a story from the MBCC website; the term was coined by Khevin Barnes (*Coding Journal*, 2020-2021, p. 50) where he asked to change the name of some procedures to sound more masculine.



Figure 5.13: Alyson Baker (2020) Manogram video still

# 5.6. Exhibition, review of artwork and audience feedback

The exhibition at Karma Collab Hub 47 Lemana Lane, Miami, on Saturday 16 October 2021 was intended to evaluate what changes may be necessary for assessment and exhibition in Toowoomba at USQ for December and January 2021. I curated and installed the exhibition myself and was keen to find out how an audience would respond to the artworks. To my surprise there was a high level of interaction with the artworks; I observed people sitting at tables and reading the *Artist Journals* (2028-2020; 2020-2021; 2021) and *Coding Journal* (2020-2021); as I observed people in the gallery space, I saw the black light shining on the *Illumination* (2021) drawings, people were reading the didactics next to the artworks and listening to *Conversations* (2015-2016) with cordless headphones. The *Manogram* (2020) video was played on a large screen above *Standard* (2018-2021) the sound of the video was initially turned on, then turned off so that the viewers could associate the knitting process with the knitted artworks in *Standard* (2018-2021). People came up to me and asked questions about the artwork and how the *Coding Journal* (2020-2021) was made, some commented that they had no idea that men could get breast cancer. Unfortunately, one viewer did tell me of a spelling error in one of the *Illumination*" (2021) drawings, this was amended for the final exhibition for assessment in Toowoomba.



Figure 5.14: Julie Hillocks Shinners, Exhibition Photograph of Alyson Baker's *Illumination* (2021), taken at USQ Arts Gallery, Toowoomba Campus, 10 December 2021

In the exhibition on the Gold Coast, I gave an opening speech, and as the exhibition was for one night only, I told the audience that the exhibition intention was to be interactive. I invited the audience to read the *Artist Journals* (2018-2020; 2020-2021; 2021) and *Coding Journal* (2020-2021), I told them to take torches and shine a light on how men felt having a stereotypical women's disease, I asked that they pick up any of the *Flong* (2021) series and find the hidden feelings, I placed headphones for the video in easy reach. In informing the audience in my speech, then opening the doors to the exhibition it also allowed for an expectation, a build up to

the actual viewing of the artworks. As one viewer told me, because there were 60 people that needed to share torches, they had to wait for the headset to watch the video, this created an anticipation and I observed that people were keen to engage with the artworks and I received some unsolicited feedback (Refer Appendix G1).

When installing for the USQ exhibition in Toowoomba, I originally intended to guide the audience around the gallery space and explain as how to engage with the artworks. However, as I was advised by the USQ Arts Gallery team that opening nights were not being conducted due to COVID-19, so I could not give an opening speech and discuss the particular audience engagement and so, I needed to brainstorm alternative ways to inform the audience of the participatory nature of the exhibition. In collaboration with USQ curator, Brodie Taylor, we made didacts to explain the interactive modalities of the artworks and invite the audience to use torches to illuminate drawings, to pick up any *Flong* (2021), to read the *Journals* and to listen with headsets to the videos which were placed next to the artworks. To inform the artworks and displayed this at the entrance to the exhibition

I discovered that by putting on an exhibition prior to the final assessed exhibition provided opportunities to amend any glitches but it was also an affirmation that the artworks would engage an audience and did present new knowledge about male breast cancer to educate and advocate for male breast cancer patients. I have included feedback from some of the audience in Appendix G1. I was also grateful to the people who reviewed my artworks during the research process, copies of the feedback are contained in Appendices H1-7. I was flattered that Professor John Boyages AM, took an interest in the research and offered information to include in the *Poster* (2021) as well as reviewing the initial layout. I am very grateful to Dr Julia Pitcher, for reviewing *Manogram* (2020) video and suggesting that the knitted process and audio was more appealing than the raw video, and that it would be a useful resource for advanced medical students. I was overwhelmed by Ann Fincher's feedback, Rob Fincher's widow, her comments affirmed that my artwork could make a difference to others. Finally, I am eternally grateful to Rod Ritchie, for allowing me to interview him twice, during my Honours research and again through this DCA, for his review and feedback on the artwork and his generosity in allowing me to use his ultrasounds in the *Illumination* (2021) series.

### 5.7. Renaming or reclassifying male breast cancer

The idea of renaming breast cancer for men to "chest cancer" was brought to the Male Breast Cancer Coalition during an online forum in February 2021. The speaker was Matthew Knowles, Beyonce's father, he was deployed as a celebrity figure who could spear head male breast cancer awareness; his decision to refer to his cancer as "chest cancer" caused a rift in the male breast cancer community and male patients remain divided on this issue (Ritchie, 2021). As Ritchie (2021) explains, the issue of renaming breast cancer to "chest cancer" for men is seen by some as undoing the previous advocacy. As I reflected on Matthew Knowles' idea, I wonder should male breast cancer be reclassified rather than renamed? The rationale for this question comes from following up on a comment made by my principal participant, Rob Fincher (2016), who wondered if there wasn't something medically that would help men with breast cancer. I began researching medical journals and this finding was described in Section 5.2 and indicates that male breast cancer appears to be different to female breast cancer (Lordso et al. 2017, p. 289). In response to these medical findings, some medical experts are advocating for malespecific breast cancer research (Bolger 2016; Reis et al. 2011, p. 106).

My question is that perhaps there is a need to reclassify male breast cancer completely for men; perhaps this is what is needed when we exist in a society under a patriarchal system (Connell and Messerschmidt, 2005, p. 832). Currently males are excluded from medical surveillance despite family history of the disease (R Ritchie 2019, pers. comm., p. 11), are denied access to medical rebates for clothing essential for their recovery (Michael C, cited in MBCC, 2016), and in some countries, insurance does not cover their medical expenses because the criteria for government funding and access to some services are that breast cancer patients are female (Ben-Kely, p. 31; Carr, p. 32; Goldstein, p. 35; Grates, p. 35; Holmes, p.36; Holmes, p.37; Kriz, p. 38; Ritchie, p. 41 cited in *Coding Journal*, 2020-2021). Perhaps reclassifying breast cancer for males is an appropriate alternative, it could then be promoted under the umbrella of a "male cancer" and as such attract government funding and research. Perhaps it would reduce the stigma for men, and they would feel more

likely to seek medical attention earlier and come out with their experience. This in turn could create more awareness of the disease, allow for an environment of support systems for men to overcome trauma of having the disease, and increase survival for patients. Reclassifying breast cancer is a direction I would like to pursue in future research but in the meantime, this disease needs to be promoted as genderless.

## 5.8. Concluding remarks

My contribution as an artist was to advocate for male breast cancer through my creative outcomes of this research. It was through the data analysis that I was able to create artworks that gave a visibility and voice to the male experience, and I juxtaposed the male with the female experiences to create a gender inclusive model. What I had not expected when I first began this Doctor of Creative Arts was that the analytical process could become artworks. Grounded Theory allowed me to take the data coding and apply it directly into the artwork. I coupled Grounded Theory coding with Autoethnographical representations of men with breast cancer so that I could engage in an emergent process (Charmaz 2008, p. 161). I read the stories with no preconceived ideas and wrote pivotal statements from 24 stories until I felt I had saturated the analysis (Charmaz 2008, p. 167). I then created and named the theoretical categories to reflect the pivotal themes in the stories. For example, when I read some men did not know they could get breast cancer – it was "unexpected" then I used this term as a theoretical category.

By making a palimpsest I extended my arts practice and contributed to the arts field with the concept of *Illumination* as an inversion of *erasure*. It was by defining the theoretical categories that I serendipitously found the print making process of "stereotype" and amalgamated the materials and concepts of this modality to represent the quotations and images that emerged in the data analysis. Using Grounded Theory coding helped me to not only understand and analyse the 167 stories, it also provided artistic materials and concepts that could be included in artworks. By documenting in calligraphy, direct quotations from the stories, they became evidence of each theoretical category and materials for artworks. The documentation of my research process in the *Artist Journals* (2018-2020; 2020-2021 and 2021) and the *Coding Journal* (2020-2021) in calligraphy also became artworks

for exhibition. I would have never imagined it possible if I had not engaged in Ground Theory coding as a methodology to understand the male experience.

This DCA is by no means definitive, there is still a need for further investigation into artistic outcomes that raise awareness of the disease for all genders. As a start, I would recommend future research to investigate the possibilities of renaming and/or reclassifying male breast cancer, to ascertain how, if possible, this would benefit minority cohorts such as men and transgender breast cancer patients. In the meantime, the artwork that has emerged from this DCA and future artwork that may evolve from this research, will continue to be shared through exhibitions and promotion through breast cancer agencies, so that male breast cancer is devoid of stigma, that the diversity of patients are provided for, included, and represented in images and dialogue about breast cancer.

Finally, I returned the research question and asked myself how my creative outcomes had subverted the current awareness paradigm. I achieved subversion by documenting in artwork how men felt having a stereotypical "women's disease", the artworks allowed the viewers to consider alternative inclusive representations of breast cancer (see Appendix G1). By giving males visibility and voice I advocated for inclusive breast cancer narratives with the broader art and medical communities. This is exemplified by the invitation to publish *Poster* (2021) on the BCNA Health Professionals website (See Appendix F4) and from feedback by viewers at the exhibition. I felt the pivotal feedback, which was contained in an email from BCNA (Appendix F4), came from my principal participant Rod Ritchie, where he responded to a request for feedback about *Poster* (2021).

"That's me on the poster and I am very pleased with the final result."

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## APPENDICES

Appendices A to M can be found in Volume II of this thesis.