Shifting Masculinities Amongst Men Diagnosed with Breast Cancer: A Multi-Method Phenomenological Inquiry

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Publications

Parts of this thesis have been published:


Abstract

Under-acknowledged both clinically and socially as a threat to men’s health, breast cancer in men continues to be a critical health issue, with complex ramifications for those affected. Research exploring men’s breast cancer experiences and their lives beyond the diagnosis remain limited. Hence, this inquiry asks ‘How do men describe breast cancer and their experiences of the illness?’ the aim, to advance understandings about men’s meaning-making of breast cancer and masculinity, and to ‘give voice’ to this under-researched population.

Embedded theoretically and methodologically within a critical qualitative health framework, the research has two parts. Part one is a qualitative synthesis of nine existing international studies exploring men’s breast cancer experiences, following Noblit and Hare’s (1988) method for synthesising interpretive qualitative data. The outcomes of this synthesis were used to inform part two: a multi-method phenomenological exploration of men’s breast cancer accounts using verbal and visual data. Thirty-One British men recruited through NHS records, Breast Cancer Care, and social media platforms, used self-authored photographs to illustrate their breast cancer experiences, which they later discussed as part of extended semi-structured interviews. All data were analysed together using Interpretative Phenomenological Analysis (Smith & Osborn, 2003).

Integrating and triangulating the findings from the two study phases, the on-going marginalisation of men across the breast cancer trajectory, and how this influences men’s experiences of, and adjustment to the illness, are revealed. Findings from the qualitative synthesis suggest current approaches to breast cancer care and advocacy serve to isolate men, potentially alienating and emasculating them; while patient management practices and informational resources unequivocally marginalise men. Findings from the new inquiry corroborate those from earlier studies, further illuminating the difficulties men encounter and some of their coping strategies. Specifically, three superordinate masculinities were identified: ‘threatened and exposed’, ‘protected and asserted’, and ‘reconsidered and reconfigured’. A schematic representation is presented to show how these interconnected masculinities are encountered, performed and utilised by men from pre-diagnosis through treatment and beyond as they manage, make sense of, and live through breast cancer.

How and why men encounter/perform these different masculinities at different points in time across the breast cancer trajectory, and how this aids men’s adjustment to illness, and life beyond the diagnosis, is considered. The findings are expected to have both academic and real-world impact through informing future research, and recommendations for advocacy and intervention for improved future breast cancer care and practices.
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Chapter 1 – Thesis outline

1.1 Setting the scene – topic and focus of the thesis

Breast cancer is the most common cancer in the UK, with approximately 150 cases diagnosed every day; one every 10 minutes (Breast Cancer Care, 2017). However, its incidence among men is low, accounting for fewer than one-percent of all UK breast cancer cases, affecting around one in every 100,000 males; a ratio of 1:143 men to women (Office for National Statistics, 2014). Around 400 new cases present in men yearly in the UK, compared to the estimated 55,000 women diagnosed (CRUK, 2017). Subsequently, breast cancer in men is frequently overlooked within both lay and expert healthcare systems (Iredale, Brain, Williams, France & Gray, 2006), despite breast cancer being responsible for proportionally more male deaths annually than penile or testicular cancers (CRUK, 2017). Prognosis for men and women is similar, yet outcomes tend to be poorer for men due to reduced illness awareness and resultant late detection (Rudlowski, 2008); five-year survival rates vary depending on disease staging at diagnosis but are generally poorer for men (80.8%, CI 95%) than women (86.6, CI 95%) (Public Health England, 2014).

Causes of breast cancer in men remain unclear, though a number of possible risk factors are indicated. Incidence, as with women, has strong links with aging and is most common, though not exclusively, in men aged over 60 (Ruddy & Winer, 2013; Breast Cancer Care, 2017). Men with a family history of breast cancer also have an increased risk of developing the illness, with up to 1 in 10 men who inherit a BRCA2 gene mutation affected (Macmillan Cancer Support, 2014; Martin & Weber, 2000). High oestrogen levels, radiation exposure, hot working environments, obesity and some genetic and medical conditions (e.g. Klinefelter’s syndrome; Cirrhosis) also suggest an elevated lifetime risk for men (Swerdlow, Schoemaker, Higgins, Wright & Jacobs, 2005). Clinical diagnosis and treatment methods are currently the
same for men and women, despite little evidence validating the efficacy of treatment options used with women in men (Fentiman, 2016). Unhelpfully, the illness in men is often referred to as ‘male breast cancer’, implicated as being a unique typology of breast cancer when it is not (Branney, Witty & Eardley, 2014); and, though there are different types of breast cancer, men develop the same types as women, with invasive ductal carcinoma (sometimes called infiltrating ductal carcinoma) presenting the most frequently in both sexes (Giodarno, 2005). Despite sharing some oncological similarities, socially, breast cancer in men is distinct from the disease in women. Although breast cancer is not a sex-specific condition, it is consistently afforded a gendered status, notably as a ‘women’s illness’ (Branney et al., 2014). Increased prevalence and high-profile awareness-raising, advocacy and activism around breast cancer in women over time has led to pervasive feminisation of the illness, and a reinforced perception of breast cancer as a women-only concern. This gendering of breast cancer serves as a barrier to men, deterring them from seeking prompt medical attention and professional and social support, and increasing due sensitivity to body image concerns (Ying, Agrawal & Cheung, 2005; Iredale et al., 2006).

Existing ideologies about breast cancer and femininity oppose central masculine ideals and social constructions of what it means to be a man (Williams, Stephenson & Keating, 2014; Donovan & Flynn, 2007). Breasts, particularly in Western societies, are symbolic of a woman’s femininity and sexuality; representative of biological sex and psychosocial gender. Anatomically however, both men and women have breasts (Branney et al., 2014), yet Western society typically rejects and/or ridicules the idea of men’s breasts (Williams et al., 2014). Thus, the prototypical breast cancer patient is she: she is a woman, somebody’s wife, a mother, sister or daughter, blameless in her cancer plight, and in need of global support (King, 2006). Breast cancer is frequently culturally depicted as a feared and serious threat to
mortality, synonymous with vulnerability and distress (Puntoni, Sweldens & Tavassoli, 2011), whereas Western societies typically expect men to be strong, stoical and invulnerable, even when faced with adversity (Green, 1998), and typically places heavier constraints on men than women to meet with gender norms (Williams et al., 2014). Gender and masculinity are both hierarchical social constructs; context-relative based on power relations between both men and women, and men and other men (Robertson, 2007). Being male can both confer and deny men certain privileges (Williams et al., 2014), and the extent to which men adhere to the norms of hegemonic masculinity (Connell, 1995) can have important ramifications for their health; physically, psychologically and psychosocially. Thus, men developing breast cancer is incongruent with traditional conceptions of ‘being’ male and serves to threaten men’s identities; having the propensity to create further psychosocial crises in addition to the expected challenges that a primary cancer diagnosis poses to patients’ sense of self (Robertson, 2007; Branney et al., 2014).

Current conceptualisations of breast cancer and the related ‘pink ribbon culture’ (see Sulik, 2011) further perpetuate gendered beliefs about the illness. The pink ribbon has come to symbolise breast cancer, resulting in interventions to improve research, patient practices, support and services for women (Kaiser, 2008; King 2006). ‘Pink ribbon culture’ engages the wider community in support of women with breast cancer (Gibson, Lee & Crabb, 2015), making this the dominant representation, despite its non-inclusive nature. Feminised movements (e.g. ‘Race for Life’, CRUK, 2017) thereby foster marginalisation and disempowerment of those on the breast cancer periphery, including men (and nonconformist women). Though typically not intentional, nevertheless, this is a by-product of how these movements are organised and constructed; having the propensity to alienate and emasculate
men and, in turn, impact on their psychological response to the illness (Bunkley, Robinson, Bennett & Gordon, 2000).

Despite the plethora of literature on breast cancer in women and an increased interest in men’s health (Wilkins & Kemple, 2011), there is a dearth of psychosocial research exploring breast cancer in men; especially from the perspective of men affected by the illness. Inadequate knowledge and awareness about breast cancer and breast health generally in men persists at public and professional levels (Al-Naggar & Al-Naggar, 2012; Thomas, 2012), potentially having grave implications for men, and possibly leading to unnecessary deaths. In order to improve understandings regarding disease manifestation in men, and the extent of the apparent inequities faced by men with breast cancer, further experiential research is essential to capture the perspective of men affected by breast cancer. Specifically, there is a need to determine how some of the needs of men diagnosed with breast cancer differ from those of women; what the breast cancer experience means to men, and for them, in terms of their identities, masculinities, relationships and embodiment; how and whether changing current approaches to breast cancer and associated patient practices and services might improve men’s breast cancer experiences; and, what changes (if any) men themselves desire.

1.2 Thesis statement

Empirical evidence to date, albeit limited, proposes that current approaches to breast cancer care and advocacy inadvertently serve to marginalise men who develop the illness, posing a host of secondary issues (e.g. psycho-emotional, psycho-social and psycho-sexual) in addition to the primary challenge of a cancer diagnosis; having implications not only for the men themselves, but significant others too – be those familial or health professionals (Donovan & Flynn, 2007). Action is therefore required at all levels if the inequities facing men with breast cancer are to be successfully confronted, and a rethinking of breast cancer – both clinically
and socially – is to emerge. The lack of studies to date on men and breast cancer, especially the lack of experiential knowledge, plus the continued global interest in health inequalities and the health and well-being of minority groups in underprivileged circumstances, provides a clear rationale for exploring men’s breast cancer experiences, and the issues these men contend with. The purpose of this thesis is therefore to advance understandings about men and breast cancer by exploring, in-depth, the lived experiences and meaning-making of men affected by the illness.

This two-part inquiry first explores the extant (qualitative) literature base by way of a qualitative synthesis; the outcomes of which are used to inform a new multi-method photo-phenomenological study. Specifically, the research considers men’s verbal and visual representations of the breast cancer experience, using a combination of qualitative psychological research methods; an innovative, synergistic approach to the study of men and breast cancer, designed to accomplish greater insight and a more comprehensive understanding of the illness experience from the perspective of affected men. Men’s experiences of breast cancer have yet to be explored using visual methods, and/or using an integrative verbal-visual method such as that applied here. Therefore, this multi-method approach will not only complement the current (small) body of verbal and/or textual data available, but also offer a fresh, unique contribution to the field of study; demonstrating in greater depth the complexities of men’s breast cancer experiences and masculinities, lending new strength to the argument that breast cancer in men is a marginalised malignancy, with men on the periphery of optimal psychosocial care and support (Quincey, Williamson, & Winstanley, 2016). The findings are expected to have both academic and real-world impact through informing recommendations for advocacy and intervention for improved future care.
and breast cancer practices; thus, further indicating the importance of this research contribution.

Several theoretical and methodological perspectives underpin this thesis which has an inter-disciplinary focus, though it is principally informed by Critical Health Psychology (CHP); a distinct arm of health psychology (Marks, 2002) differing from other, especially mainstream, approaches by critically discerning traditional theories, methods and practices, and proposing radically fresh agendas that challenge these dominant standpoints (Hepworth, 2006). Emerging out of the broader critical debates within psychology and the social and health sciences (Murray, 2015), CHP assumes a unique position, criticising health psychology whilst simultaneously appraising the challenges facing CHP, i.e. it is self-critical at the intra-disciplinary level (Hepworth, 2006). Issues such as stigmatisation, marginalisation, social exclusion and identity creation, and constructs like gender and sexuality, are at the centre of CHP’s research interests (Chamberlain & Murray, 2008), demonstrating its suitability as an epistemological grounding for exploring socially marginalised groups, such as men with breast cancer. Drawing also on the tenets of Phenomenological Psychology (Smith, 1996) and some components of Participatory Research (PR; Cargo & Mercer, 2008) – both of which share essential core concepts with CHP, justifying this epistemological fusion – the research appropriately adopts an innovative, integrative conceptual framework, incorporating phenomenological and visual methodologies and methods, with all data analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009); a popular analytic approach for inquiries of a critical qualitative health nature, and those exploring hard-to-reach populations (Pringle, Drummond, McLafferty & Hendry, 2011), like men who have experienced breast cancer.
The research questions are explored and the analyses discussed according to concepts and theories relating to men’s health studies, including masculinities (e.g. Connell, 1995), embodiment (e.g. Watson, 2000), gender (e.g. Pleck, 1995), and holistic psychosocial oncology (e.g. Baker, Beesley, Dinwoodie, Fletcher, Ablett, Holcombe et al., 2012; Thewes, Butow, Girgis & Pendlebury, 2004). Staying true to IPA paradigm, the research process is consistently deliberated and reflected upon throughout the thesis; ensuring that the research findings represent the ‘voice’ of men affected by breast cancer, whilst simultaneously recognising the active role of the researcher in this process (Smith, Jarman & Osborn, 1999).

1.3 Structural overview of the thesis

In this preliminary chapter, the research topic and focus of the thesis is presented, together with the statement of intent summarising the scope, purpose and direction of the thesis; how the researcher plans to illustrate and support this argument, and what the thesis is expected to demonstrate.

Chapter 2 provides the introduction. Here, men, breast cancer and masculinities are considered contextually, theoretically and empirically (insofar as the quantitative story so far), demonstrating why breast cancer in men presents as a critical health issue in need of research attention, before outlining the research questions and aims of this specific inquiry.

Chapter 3 presents the first part of the two-part study; the qualitative synthesis. The chosen method of qualitative synthesis (meta-ethnographic) is discussed and the process itself explained, before assessing the outcomes of synthesising nine existing qualitative studies exploring men’s breast cancer experiences, and articulating how the findings serve to inform the new multi-method study (part two).
Chapter 4, the methodology chapter, explains the integrated multi qualitative approach that is adopted for the research inquiry. Together with Chapters 2 and 3, the methodology provides a firm foundation on which to develop the second half of the two-part study, and the analysis that follows.

Chapter 5 outlines the method for the second study phase; a fresh qualitative inquiry combining verbal and visual data collection methods, specifically semi-structured interviews together with participant-authored images. Here, recruitment and sampling strategies are discussed alongside ethical considerations, the study procedure and analytic strategy.

The empirical findings from the multi-method inquiry are presented, analysed and discussed in Chapters 6, 7 and 8. The extensive findings are organised according to a schematic representation of three masculinities identified across the men’s data; illustrating how the men performed and utilised masculinity across the breast cancer episode, as they navigated their way through the illness experience. Chapter 6 introduces and explains the schematic representation, along with the first of the three superordinate masculinity themes identified: ‘threatened and exposed’ masculinity, exhibited in the early stages of illness following formal diagnosis, when the men first recognised their health and social vulnerabilities. In Chapter 7, the second superordinate masculinity theme is presented and discussed: ‘protected and asserted’ masculinity, illustrating the men’s desire to preserve their male identity and uphold leading social positions; typically performed after the men realise their threatened and exposed positioning as men diagnosed with breast cancer. Finally, Chapter 8 considers the third and final masculinity identified: ‘reconsidered and reconfigured’ masculinity, exhibited by the men post breast cancer treatment as they advance towards illness recovery; demonstrating some of the men finding benefit(s) and positives in the breast cancer experience.
Chapter 9 provides a general discussion, evaluating the findings in view of the research aims and questions, and the theoretical and methodological underpinnings of this inquiry; demonstrating how the research serves to advance understandings about men and breast cancer, contributes to academia, and has real-world impact. Future directions for research on men and breast cancer are also presented in this chapter, alongside recommendations for clinical care, practice and policy, and the researcher’s reflexive account and concluding remarks.
Chapter 2 – Introduction

In complement to Chapter 1, which justifies the need, establishes the aims and outlines the structure, this chapter contextualises the research; presenting an overview of men’s health and masculinity, related theoretical perspectives (including gender role strain (Pleck, 1995), Connell’s (1995) relational model of masculinity, Watson’s (2000) male body schema, and Bury’s (1982) biographical disruption), and an overview of key quantitative findings in the field regarding men and breast cancer. It also explains why breast cancer in men presents as a critical health issue, before stating the research aims and questions.

2.1 Contextualising men’s health

2.1.1 Men’s health and the role of masculinity(ies)

Increasing in popularity since the mid-1980s, and particularly since Sir Kenneth Calman’s influential report in the early 1990s, formally recognising the serious health problems facing men in the UK (Baker, 2017); men’s health has become an area of major interest and importance on a global scale (Robertson, 2007). Once almost a taboo subject, men’s health, especially men’s mental health, is now prominent in today’s media, both off- and on-line, and also in the realms of research and academia, with ‘Men’s Studies’ now a recognised field in the social sciences (Broom & Tovey, 2009). With research into men’s health proliferating, how it is defined and conceptualised is constantly evolving. To date, arguably the most important conceptual shift is the move to recognising that men’s health is not devoid of wider social and economic determinants of health (Robertson, Williams & Oliffe, 2016). Previously, the tendency had been to (over)focus on the individual, and to blame men themselves for their health behaviours and outcomes; however, scholars have since realised that the male perspective on health is not developed in isolation, rather, the person and the social are intertwined (Sheldon & MacDonald, 2009). Thus, current thinking considers that to
understand men’s health is to understand the ways in which social constructions shape men’s everyday lives, and their experiences of health and illness accordingly (Griffith, Gilbert, Bruce & Thorpe Jr., 2016). The social production of health and illness among men is now receiving an explicit gender focus (Annandale & Hunt, 2000); and, also how men enact masculinity in health and illness contexts has and continues to attract considerable research attention (Robertson et al., 2016).

In her foreword to Gough and Robertson’s (2010) book ‘Men, Masculinities and Health: Critical Perspectives’, Hunt (2009, p.1) asks “why should we care about men, masculinities and health?” The answer to this is for an abundance of reasons, though not least because, in most parts of the world, men continue to experience considerably worse health outcomes than women; a gender-based health disparity that until relatively recently had received little attention from healthcare providers or policymakers at every level (Baker, Dworkin, Tong, Banks, Shand & Yamey, 2014). The so-called ‘men’s health gap’ presents as an interesting paradox, as in many societies men (compared to women) still enjoy the lion’s share of opportunities privileges and power in most domains, excluding health (Baker et al., 2014). The Global Burden of Disease Study 2010 (see Wang, Dwyer-Lindgren, Lofgren, Rajaratnam, Marcus, Levin-Rector et al., 2012) showed that throughout the 40-year period from 1970 to 2010, women had a comparatively higher life expectancy than men, outliving them by an average of almost six years. Further, men are more vulnerable to major life-threatening chronic diseases (Vlassoff, 2007), are more likely than women to die of almost every disease and illness (Sorenson, 2011), and are nearly twice as likely to develop and die from virtually all of the cancers that can affect both sexes (Remes, Wainwright, Surtees, Lafortune, Khaw & Brayne, 2016).
With overall increases in human longevity, health inequalities have grown (Bushe, 2013). While some of these inequalities are attributable to natural biological differences or free choices in lifestyle, it is now widely accepted that social determinants are responsible for significant levels of unfair health ‘inequities’ (Royal College of Nursing, 2012). Hence, Marmot’s (2017) recent call for action on the social determinants of health; a social movement he claims is vital for achieving health equity. Of the various determinants of poor health and illness that classify as ‘social’, gender is shown to be a significant factor; thus, gender analysis is thought to be key to understanding the experience of health, and how illness might be prevented (Vlassoff, 2007).

The health-related deficits that men experience can and have widely been attributed to masculinity (Gough & Robertson, 2010). The concept that masculinity can be problematic for men’s health first came to prominence in the late 1970’s, following Harrison’s (1978) proposition that male sex-role socialisation may endanger health; a thesis which still holds weight in contemporary psychosocial explanations of men’s health. Much attention has since been paid to the role that traditional masculinity and/or masculine roles and beliefs play in men’s health and illness behaviours and outcomes (Galdas, Cheater & Marshall, 2005). Several negative social consequences have been linked to masculinity; in health terms, it is seen to lead to: greater exposure to risk and a propensity for risk-taking; health-damaging behaviours; and a reluctance to seek help and/or show weakness; practices all commonly associated with ‘real’ men (Robertson et al., 2016). In this respect, as Hearn (1996, p.213) explained, masculinity is ascribed “causal power” and viewed as if it operates independent of the individual in determining men’s health practices; essentialising ‘what men are’ and not considering ‘what men do’, as has become the preferred focus (Robertson et al., 2016). Some researchers (e.g. Hunt, 2009) argue that pathologising and homogenising masculinity in this
singular way is unhelpful, as it oversimplifies the men’s health gap; “masking the complex, and sometimes, contradictory nature of masculinity in health and illness contexts” (Gough & Robertson, p.1).

Indeed, how masculinity and health are thought to interact varies according to how both are conceptualised (Robertson et al., 2016). Despite its importance, ‘masculinity’, or rather ‘masculinities’ (see section 2.2.2), is an unclearly demarcated concept that is defined and understood differently by people depending on their social and cultural contexts. Understandings are not universal; therefore, the concept does not have uniform meanings and negative influences within and across all men’s lives (Creighton & Oliffe, 2010). The ever-evolving literature on gender and health continues to debate whether or not masculinity is in fact primarily a barrier or a portal to health (Griffith et al., 2016). Against a plethora of negative associations, some studies report positive relationships between masculinity and health (e.g. Levant & Wimer, 2014). Socially constructed masculinity is therefore a fluid and flexible concept, and as such, men are able to manipulate it as they see fit according to time space and context, and in line with their own abilities, which can be advantageous (Coles, 2008). Men may look to masculine ideals and reformulate these in establishing their own ideal masculinity; one which they have the capacity to perform and which validates their manliness in their own given contexts (Griffith et al., 2016). Thus, how men individually conceptualise masculinity is an important determinant of men’s health, influencing health-related decisions and behaviours (Evans et al., 2011); these, the products of their own socially and culturally bound thoughts about what it means to be male and a man (Creighton & Oliffe, 2010).

‘Men’ are not simply one homogenous group, rather the gender category is made up of many individuals who identify as ‘male’; all of whom arrive at the health/illness arena from
different social and cultural backgrounds, and positions of power. Consequently, men may respond differently to health, illness and masculinity, not only in comparison to women, but *between* men of differing groups, e.g. age, ethnicity, socioeconomic status (SES) (Galdas et al., 2005). Further, men’s illness responses are unlikely to be the same across conditions; rather they are illness-specific, adapted according to the perceived threats to life and their male identities, both of which may influence illness behaviour (Pepper & Nettle, 2014). For instance, men diagnosed with prostate cancer, the stereotypical ‘men’s cancer’, compared to breast cancer, which is stereotypically gendered female despite affecting both sexes, are likely to respond to the diagnosis differently (Lee & Jones, 2009).

To quote Hearn (1996, p. 214) “masculinity has certainly served a purpose in developing a focus of attention on men; the question is whether it has served its purpose”. Twenty years later, Robertson and colleagues (2016) argue why it is still important for men’s health research to retain a focus on masculinities – importantly recognising plurality – and considering what the possible implications are in doing so for men’s health, policy and practice. Similarly, the current researcher demonstrates the significance of exploring masculinities when studying men’s health, specifically in the context of men and breast cancer; using a new masculinity schema to explain how men utilise and perform masculinities in experiencing the chronic illness episode (see Chapter 6).

### 2.1.2 Men’s health through a critical qualitative health psychology lens

Only in recent years have researchers begun to move away from mainstream oversimplified ideologies about men’s health and masculinity, to consider the complexities associated with men, health and masculinity, and produce more critical analyses (Gough & Robertson, 2010). Recognising that a critical approach is required if the situation with men’s health is to improve has seen a noticeable shift in theoretical, methodological and empirical approaches to
research in the field (Annandale & Hunt, 2000). In contrast to mainstream men’s health studies, which have tended to over-essentialise men health and masculinity, critical perspectives on the health of men appreciate the complex interplay of a range of factors associated with men’s health/illness circumstances (Lohan, 2007). Critical studies have advanced understandings about men’s health by challenging dominant biomedical conceptualisations, exploring issues of both individual and systemic power, interrogating relations between agency and structure, and incorporating the analysis of identities and subjectivities (Crawshaw, 2009). There has also been a shift in focus from illness to health, with attentions turning to how regulation of lifestyle and behaviour can mediate future illness potential; something which may be particularly relevant to men’s health, given that the practice of traditional masculine behaviours can increase men’s potential for future illness, e.g. delaying help-seeking (Crawshaw, 2009).

While the argument for adopting a critical approach to men’s health is now widely accepted, gaining a critical understanding about men’s health inequalities is, as Horrocks (2012, p.76) said “a highly complex task”, as there is still considerable confusion surrounding both men’s health and health inequalities (Schofield, 2000). As mentioned earlier, men are not a homogenous group, and not all experience health disadvantage; intersecting factors have a determining influence, including biological, socio-cultural and economic aspects amongst others (Horrocks, 2012). Consequently, explanations are seldom straightforward; as the current context of men and breast cancer illustrates. Reducing men’s health inequality therefore requires an interdisciplinary approach with intersectional solutions that cross research, policy and action, and critically involves those directly affected by the inequities associated with the illness (Szaflarshi & Vaughn, 2015). Hence, the research presented is principally informed by Critical Health Psychology (CHP, see Murray 2015); an approach to
health which adopts a broader social perspective, and stresses the importance of the socio-cultural and -political dimensions of health and illness. It also, in part, draws on Participatory Research (PR; Cargo & Mercer, 2008), which breaks down traditional distinctions between research and action by working collaboratively with research communities rather than imposing a framework on them (Murray, 2015). The selection of these epistemologies, how they inform the research methodology and the chosen qualitative methods, and their appropriateness in the context of men and breast cancer, is discussed further in Chapter 4 and reflected upon in Chapter 9.

**2.2 Theorising men’s health, masculinities and breast cancer**

In addition to drawing on the critical frameworks mentioned, the research also draws upon mainstream theories of men’s health and masculinities in furthering understandings about men and breast cancer. A wide range of theories and models exist from across related disciplines which attempt to understand the relationship between men’s health and masculinity/ies, from biological explanations, to role theories, and more recently, relational models; though some arguably demonstrate greater applicability to understanding men and breast cancer than others.

**2.2.1 Role theories, masculinity and health**

Proffered as an alternative to biological-determinist explanations of masculinity and health, which posit masculinity as a genetic predisposition or innate drive that negatively influences men’s health (Clare, 2001); role theory (see Parsons, 1964) assumes that conformity to traditional male roles is detrimental to men’s health, and, that failure to live up these roles and societal expectations can lead to negative affect, and in turn ill-health, resulting in what Pleck (1995, p.11) describes as “male gender role strain”. According to Pleck, the greater an individual internalises socio-cultural norms of masculinity, the greater the role strain
experienced when they are unable to meet with these male ‘norms’. This could explain why men with breast cancer exhibit strain, as often breast cancer treatment prescribes necessary role changes which either temporarily or permanently alter behavioural (male) norms, e.g. refraining from physical labour. However, role theory as a theoretical basis for understanding masculinity has been heavily criticised across social science disciplines for multiple reasons, including; that it overlooks the complexity of gender identity, failing to address issues of power relations between the sexes (Segal, 1997); and, that despite being offered as an alternative to biological-determinist explanations, it still presents as an essentialist way of thinking by expressing gender relations as binary, i.e. sex differences (Connell, 1995).

That said, some explanations that come under the role theory ‘umbrella’ may still be applicable in the context of men and breast cancer. For instance, Threatened Masculinity Theory (see Mishkind, Rodin, Silberstein & Striegel-Moore, 1986). This contends that in cultures and societies where traditional distinctions between men and women are dissipating (e.g. Western contexts), the male body serves not only to distinguish men from women, but as the primary symbol of masculinity (Ryan, Morrison & McDermott, 2010). Research has shown that conformity to gender-role traditionalism in men is positively correlated with the drive to attain the normative muscular male physique, and also distress at not having or losing muscularity (Kimmel & Mahalik, 2005). Thus, this may explain why some men who lose muscle mass as a result of breast cancer treatments demonstrate poorer adjustment to illness (Pituskin et al., 2007), since their bodies differ from normative representations of male embodiment (see section 2.2.3). Similarly, Masculine Dysfunction Strain Theory (see Levant, 1996) also explains how rigid conformity to traditional notions of masculinity can lead to poorer health behaviours and negative health outcomes, and how the process of trying to protect against any event which threatens to disrupt the performance of male norms can lead
to additional strain. Although in isolation role theories cannot adequately explain the relationship between men and breast cancer, when taken into consideration alongside other, more holistic explanations, they may still be useful to some degree.

2.2.2 A relational model of masculinity and health

In contrast to earlier theories of masculinity, later theorisations acknowledge that an adequate theory of masculinity is one that recognises the complexities, ambiguities and contradictions associated with the concept, and therefore takes into consideration issues of power, agency and structure (Hunt, 2009; Robertson, 2007). Relational models of masculinity, or rather masculinities, which stem from the works of Connell (1995; 2000), are (currently) the closest to achieving this; realising the fluid and multifaceted nature of masculinity, and how this influences its relationship to men’s (and women’s) health. Contrary to preceding theories which tend to posit men and women as opposites, Connell’s (1995) model conceptualises gender as a set of relations between men and women, and also between men and between women; and considers that masculinities are part of and develop according to a larger system of relations or ‘gender order’. According to Connell (2000, p.24), this thinking “gives us a way of understanding the different dimensions or structures of gender, the relation between bodies and society, and the patterning or configuration of gender”. She suggests that the relational patterning of masculinity insofar as current Western gender order consists of hegemonic (i.e. the leading position), subordinated (i.e. subordinate to the leading position), marginalised (i.e. from the leading position) and complicit (i.e. the patriarchal dividend of hegemony, subordination and marginalisation) masculinities (Connell, 1995); hierarchical configurations of gender practice that men move within and between over time. These configurations are also said to interact with other social constructs too, e.g. race, sexuality and disability, and are as Connell (1995, p.81) explains “generated in particular situations in a
changing structure of relationships”; thus, are open to change, context depending, including differing health and illness contexts. This thinking acknowledges that masculinities are historically contingent without being essentially determined; fluid but hierarchical, with dominant (i.e. hegemonic) constructions becoming embedded within social structures, and the organisation of society at the expense of those subordinated to and/or marginalised from hegemonic positions (Robertson, 2007).

Thinking about this model relative to men and breast cancer, related qualitative works present these men as marginalised from the leading normative expression of masculinity (physical and representational), and also from full participation in society by material practices; though this marginalisation may be more implicit and indirect when compared to other masculinities (e.g. gay masculinity). To explain this further, as breasts are more commonly representative of female embodiment and breast cancer is typically gendered female, a man developing this disease is incongruent with what society understands as ‘being’ male; this prompting not only cultural stigmatisation but material forms of discrimination too, e.g. being excluded from participating in breast cancer advocacy and research (Quincey et al., 2016). If as Connell (1995) proposes, most men strive to attain and maintain hegemonic masculinity, then a breast cancer diagnosis interferes with this; preventing men from mirroring normative ideals, and sustaining positions of power.

Connell’s (1995) relational model, though widely used in contemporary men’s health research is not without its critics (e.g. Hearn, 2004). Much of the related critique rests on the inconsistent ways in which ‘hegemonic masculinity’ is represented understood and used, and what constitutes as dominant or leading, if this is context-specific (Ford & Lyons, 2012). Connell’s approach implies fluidity and plurality, challenging earlier schools of thought that present hegemonic masculinity as a singular concept and fixed structure, as opposed to
variable depending on time and place. Further, as Halls (2013) argues, in the context of men and breast cancer, it is necessary to consider cultural and moral orders as well as gender order, since hegemonic and marginalised masculinities cannot exist in isolation of these; rather, they are mutually constituting processes (Ford & Lyons, 2012). Despite such criticisms, this approach can still be a useful starting point from which to explore health and masculinities.

2.2.3 Contemporary theorising of masculinity

Theorisations of masculinity and how masculinities are typified and understood continues to evolve. Since the introduction of Connell’s (1995) relational model, a number of contributions have been made which serve to challenge Connell’s initial approach regarding hegemonic masculinities; notable amongst these are the notions of ‘hybrid masculinities’ (Demetriou, 2001), and ‘inclusive masculinity theory’ (IMT; Anderson, 2009).

Hybrid masculinities, as discussed by Demetriou (2001) in his critique of Connell (1995), are defined by Bridges and Pascoe (2014, p.246) as “the selective incorporation of elements of identity typically associated with various marginalised and subordinated masculinities and – at times – femininities into privileged men’s gender performances and identities”; and are primarily concerned with “the ways men are increasingly incorporating elements of various ‘Others’ into their identity projects”, challenging socially constructed systems of power and inequality. Early advocates of the concept (e.g. Demetriou, 2001) claim hybrid masculinities are widespread, and that men’s assimilation of multiple identities (e.g. gay/Black/feminine) consistent with changes in gendered meanings over time and space, are illustrative of increasing levels of equality, and a transformation of hegemonic masculinity as it was initially conceptualised by Connell (Bridges & Pascoe, 2014). Hybridisation is presented as having great potential for change, and as indicative of shifting normative constraints; a way of thinking about masculinity that men diagnosed with breast cancer, and indeed other men (and
women) who become distanced from hegemonic masculine ideals, may perceive as preferable if hybrid masculine forms are representative of changes in expressions of systems of power and inequality, and undermine dominance, as Demetriou (2001) postulated.

Following the introduction of ‘hybrid masculinities’, Anderson (2009) later presented his theory of ‘inclusive masculinities’, which also argues that: contemporary transformations in men’s gender performances are widespread; masculinity is characterised by ‘inclusivity’ not exclusivity; and inclusivity – like hybridity – is part of a process of incorporating ‘Other’, and thus fundamentally challenges systems of inequality (Bridges & Pascoe, 2014). Central to understanding IMT, is the notion of ‘homohysteria’: defined by Anderson (2009) as the fear of being socially perceived as gay; a concern often expressed by (heteronormative) men diagnosed with breast cancer (Donovan & Flynn, 2007). IMT theory contends that profound changes will occur in both conceptualisations and practices of masculinities when: ‘homohysteria’ reduces; stratifications of men become less hierarchical; and non-conforming/diverse forms of masculinities are better accepted and more evenly esteemed (Anderson & McCormack, 2016). For Anderson (2009, p.9), contemporary masculinities epitomise these significant social changes and indicate “the erosion of patriarchy”. Some scholars (e.g. Connell & Messerschmidt, 2005; de Boise, 2015) though are sceptical of whether hybrid masculinities or IMT challenge gendered systems of power and inequality as is claimed.

Both theories – insofar as their original formulations – can be criticised for their narrowed focus on young, White, middle-class, heterosexual-identified men (Bridges & Pascoe, 2014; Anderson & McCormack, 2016). Further, a number of Anderson’s (2009) claims are contentious, including: that homophobia is progressively declining; the extent to which IMT can be used to explain changing masculinities in a range of contexts (including men’s health);
and also, for not accounting for the position of women, and for failing to explain how IMT relates to the reproduction of patriarchy; though Anderson does accept these criticisms and has consequently refined the theory (see Anderson & McCormack, 2016). Additionally, while Connell & Messerschmidt (2005, as cited in Bridges & Pascoe, 2014, p.247) acknowledge that hybrid masculine forms may exist, they are critical of “the extent and reach of hybrid masculinities”. Furthermore, Bridges and Pascoe (2014) argue that whilst hybridity unequivocally blurs social and symbolic boundaries, rather than confront embedded social inequalities, hybrid masculinities distance men from hegemony and work to fortify and obscure systems of power and inequality in historically new ways, and thus present no ‘real’ challenge. Consequently, some scholars (e.g. Bridges & Pascoe, 2014, p.247) suggest hybrid masculine forms are perhaps best thought of as “contemporary expressions of inequality”.

In view of the critiques of existing notions of masculinities, Robertson, Williams and Oliffe (2016, p.64) argue that masculinities, particularly in the context of men’s health, are perhaps best understood as “configurations of social practice” and “as part of the dynamic processes involved within the “gender order” … conceptualised as both the producer and product of both social structures and human agency”. Robertson and colleagues (2016) highlight the variability, diversity and dynamism of configurations of practice, whilst recognising that they are hierarchical (in terms of associated material and representational benefits) and embedded within constrained institutions and social structures, thus limiting the opportunities made available to men to engage in varied configurations; conceptual concerns which Robertson et al., (2016) consider are critical to informing transformations in men’s health.

2.2.4 Theorising embodied masculinity

Historically, it was assumed that men were less ‘in tune’ with their bodies than women, and essentially, had a mechanistic view of their bodies (White, 2001); meaning men’s approach to
their bodies was generally “if it works, don’t fix it” (Watson, 1993 p.249). However, thinking has since progressed to recognise that men are bodily aware, in terms of both what is visibly and invisibly embodied, and show particular concern for their bodily appearance; both material and representational (Robertson, 2007). Later theoretical works, such as that by Connell (1995) postulates that masculinity and male embodiment are inherently intertwined, and that “True masculinity is almost always thought to proceed from men’s bodies” (Connell, 1995, p.45); positing the body to play a central role in maintaining (often inequitable) gender relations (Robertson, 2007). The relationship between men and their bodies is complex and, at times, contradictory, but only fairly recently has male embodiment become an explicit research focus. Thus, the literature exploring how embodied masculinity influences men’s health is limited (e.g. Buchbinder, 1998; Connell, 2000) but growing; particularly in relation to chronic illness, especially cancer (e.g. Kelly, 2009), and more recently men and breast cancer (e.g. Sime, 2012; Thompson, 2017).

Theories of embodiment are diverse and are continually evolving across disciplines. One explanation that can be usefully applied to help understand the role of embodiment in the context of men and breast cancer is Watson’s (2000) ‘male body schema’. The schema is presented as a way of understanding how embodiment in respect to men’s health can be seen as existing in four interrelated forms: Normative, i.e. ‘normal’ or idealised accounts of bodily form; Pragmatic, i.e. the functional use of a ‘normal everyday body’ to fulfil specific social (gender) roles; Experiential, i.e. physical and emotional engagement in the world; and Visceral, i.e. indirect unconsciously experienced biological processes which support bodily function and partly determine form. Watson argues that for most men, healthiness is a corporeal experience guided by normative and cultural representations of embodied masculinity, and realised through their abilities to perform everyday practices, thus relating to
the pragmatic body; the medium through which they make sense of the social world (experiential embodiment). According to Watson, understanding pragmatic male embodiment is key for researchers looking to improve men’s health, as in contrast to health professionals who prioritise visceral embodiment, men themselves are more concerned with maintaining a functioning body that enables them to perform roles as are required or expected of them; a discrepancy which he claims may explain the disconnect between men and health promotion efforts.

However, Robertson (2007) argues that Watson’s (2000) overemphasis on pragmatic embodiment is a shortcoming of his work, causing him to overlook how all four elements of his schema operate; continually interacting with one another and also men’s conceptualisations of health, to influence not only health practices, but wider social aspects of health and well-being. To illustrate this interaction in relation to men and breast cancer: changes to physical embodiment, e.g. removal of breast, affects experiential embodiment, e.g. becoming unable to reach and lift, which in turn impacts on pragmatic embodiment, e.g. unable to carry out physical tasks, which thus demonstrates a departure from normative and cultural representations of male embodiment, potentially leading to identity crisis and body image dissatisfaction.

So long as the interplay between the four elements is acknowledged like this, then Watson’s (2000) ‘male body schema’ still serves as a useful framework for exploring physical and representational forms of embodiment, and for understanding these in respect to men’s health, and indeed men and breast cancer.

2.2.5 Breast cancer as a ‘biographical disruption’

One way of conceptualising breast cancer in the context of men’s health is to posit it as a ‘biographical disruption’ (see Bury, 1982; Reeve, Lloyd-Williams, Payne & Dowrick, 2010);
that is, as an event that interrupts everyday life and the life course as it was expected to play out prior to its advent. Bury (1982) conceptualises chronic illness (such as breast cancer) as a particular type of disruptive event; one that interferes not only with the structures of everyday life, but the knowledge which underpins those structures, such that a fundamental re-thinking of life as the individual has come to understand it is required. Bury links three aspects of disruption relative to developing chronic illness, all of which seemingly relate to men and breast cancer. First, the disruption of taken-for-granted assumptions and breaching of common-sense guidelines, with alternative explanations not readily available, e.g. men (typically) assume breast cancer to be a female-only concern; second, profound disruption to the explanatory systems normally used, i.e. how men understand ‘being’ male and what constitutes male identity; and third, the response to disruption requires mobilisation of resources, e.g. attempting to normalise the critical situation by maintaining social roles, behaviours and relations. Importantly (especially where applied in the context of men’s health), Bury also discusses chronic illness as a biographical disruption in terms of wider social, cultural and economic structures; demonstrating its applicability to critical inquiries.

Biographical disruption as it was originally theorised has come under some criticism (e.g. Williams, 2000), particularly by Halls (2013) in relation to men and breast cancer, who argues that the framework is less applicable to men (than women) with breast cancer for multiple reasons, including that; these men enter a contradictory world, and do not have the social, economic and/or political resources available to them to guide them in reconstructing their self-concept post-illness. However, other studies have shown that it is possible for men to rethink their personal biographies and masculine identities and maintain a sense of self following a breast cancer diagnosis (e.g. Sime, 2012; Ackroyd, 2016). Although some of Halls arguments are valid, e.g. that illness may already feature within these individuals’ lives,
and, that biographical disruption is possibly more apparent to those in otherwise privileged circumstances (e.g. White, heteronormative men). Nevertheless, further exploration is required before the concept of biographical disruption is definitively dismissed in relation to men and breast cancer.

2.3 Men and breast cancer – a quantitative overview

Given the general dearth of research into men and breast cancer, unsurprisingly, and as with the qualitative picture (see Chapter 3), the quantitative story so far is limited. That said, there has recently been a surge in quantitative outputs from studies investigating the illness in men, though these have tended to focus on men from non-UK populations (Chen, Huang, Lewis, Szeja, Hatch, Farach et al., 2017; Lecarpentier, Silvestri, Kuchenbaecker, Barrowdale, Dennis, McGuffog et al., 2017; Gargiulo, Pensabene, Milano, Arpino, Giuliano, Forestieri et al., 2016; Johansson, Nilsson, Berglund, Lauss, Ringner, Olsson et al., 2012). The reasons for why research has neglected to focus on UK men are not fully understood; though it is likely that this may be to do with population proportions and sample size sufficiency. Due to the relative rarity of breast cancer in men, in contrast to research with women, large scale quantitative studies are comparatively scarce, and to date, no randomised control trials have been carried out with male patients (Fentiman, 2016). As a result, the management of male patients and treatment recommendations are based largely on female data, despite little evidence validating the efficacy of treatment options used with women in men. Further, recent research by Fentiman (2016) claims that breast cancer in men is not wholly biomedically congruent with the disease in women, reporting key differences in epidemiological risk factors, tumour types, molecular profiling and response to systemic therapy in men. These findings pose important implications for the treatment of men with breast cancer, and further demonstrate why the illness in men currently presents as a critical health issue; as if the
methods used to treat men are inadequate this could potentially have grave health consequences for them, even death, that may be avoided with appropriate interventions.

Quantitative studies to date present mixed findings regarding breast cancer survival in men; where some have shown the prognosis for men is similar to that for women with similar-stage disease (Marchal, Salou, Marchal, Lesur & Desandes, 2009), others have inferred that men have better survival prospects (El-Tamer, Komenaka, Troxel, Li, Joseph, Ditkoff et al., 2004), though more recent research suggests men are less likely to survive breast cancer than women (Gnerlich, Deshpande, Jeffe, Seelam, Kimbuende, & Margenthaler, 2011). Nevertheless, studies consistently report that the incidence of breast cancer in men is rising (Giordano, 2005; Speirs & Shaaban, 2009; White, Kearins, Dodwell, Horgan, Hanby & Speirs, 2011), though quite why this is the case remains unclear. Incidence and prevalence data have shown there to be differences between ethnic and racial subgroups of men with breast cancer; for example, breast cancer incidence in Jewish men is higher than among any other White ethnic grouping, irrespective of where these men reside (Matarella, 2010). Further, in a study by Sineshaw, Freedman, Ward, Flanders and Jemal (2015), incidence was higher in Black men than it was in White equivalents, and also showed Black men were more likely to be diagnosed at a younger age. Crew, Neugut, Wang, Jacobson, Grann, Raptis et al., (2007) also found five-year survival rates in the US to be considerably lower for Black men; 66% compared to almost 90% in White men, after adjustments for known clinical, demographic and treatment factors. Though this may also link to poverty and racism, with Black men able to access limited and poorer quality care, as other studies, also conducted with US populations (e.g. Matarella, 2010), have shown there to be socioeconomic differences between men. For instance, incidence in men increases with affluence. Regardless of the rarity of breast cancer
in men, the reasons for these disparities need to be better understood and demonstrate a clear need for further male-specific breast cancer research.

A wealth of statistics on breast cancer are available, though statistics on men and breast cancer *per se* are harder to source; either because they are obscured by the volume of statistics on women, combined with female data, or have simply been omitted from statistics publications altogether. For instance, the National Institute for Health and Care Excellence (NICE), World Health Organisation (WHO) and National Cancer Intelligence Network (NCIN) have all produced a number of publications which focus on breast cancer, but all of which lack detailed breakdowns of statistical information relating to men. Male-specific information is though starting to emerge (e.g. Ruddy & Winer, 2013; PDQ Cancer Information Summaries, 2017), and statistics on UK men can be made available on request from Cancer Research UK; but the fact that these are not readily published alongside statistics for UK women and in the public domain further exemplifies the inequity between men and women with breast cancer.

The body of quantitative studies investigating masculinity and health behaviour is also limited, and even more so in relation to men and breast cancer; though some male-specific cancers have attracted research attention of this nature, e.g. penile cancer (see Skeppner, Andersson, Johansson & Windahl, 2012). Psychologists have attempted to measure the relationships between masculinity and men’s health practices and outcomes by way of psychological scales, e.g. Bem’s Sex Role Inventory (Bem, 1981). However, research using such scales presents conflicting evidence as to whether masculinity confers advantages or disadvantages in terms of men’s health. Of the studies that do exist, the vast majority present masculinity as being problematic for men’s health and have tended to focus on links between aspects of masculinity and negative health behaviours, e.g. delayed help-seeking (Sharpe &
Arnold, 1998). A recent study with a sample of UK men by Sloan, Conner and Gough (2015) further demonstrated this, finding that generally, aspects of masculinity predicted worse health behaviours for men, though some aspects were linked with health promoting behaviours; this leading the researchers to infer that if more research were focused on aspects of masculinity related to positive health behaviours, more such links may be found.

2.4 Breast cancer in men – a critical health issue

Contrary to the popular belief that health and illness among men is now receiving explicit gender focus, in the context of breast cancer, men continue to reside backstage while women “take the gender spotlight” (Sabo & Gordon, 1995, p.4). Research into men and breast cancer, both biomedically and psychosocially, continues to lag behind that which is explicitly focused on women; this despite the fact that men die more frequently from breast cancer than some male-specific reproductive cancers, e.g. testicular cancer (CRUK, 2017). This under-acknowledgement of men in the context of breast cancer is not restricted to research and psychosocial academy and persists especially in the realms of breast cancer advocacy and activism; arguably for social, economic and political reasons. The evidence for this is both considerable and undeniable, particularly in relation to breast cancer promotion campaigns, which consistently overlook men, and moreover, explicitly gender breast cancer as ‘female’. Flagship movements include: Breast Cancer Now’s Wear It Pink day, which encourages people to dress in pink on a designated date within the breast cancer awareness month of October; Walk the Walk’s Moonwalk involves fundraisers walking the London Marathon route at night wearing decorative brassieres; ASDA’s Tickled Pink campaign, in conjunction with Breast Cancer Care, invites consumers to purchase limited edition pink-coloured goods; and Tesco, together with Cancer Research UK, hosts a series of Race for Life events, from sponsored walks and runs to muddy obstacle courses, which only women can participate in.
The promotional materials and imagery used to advertise these campaigns are almost entirely (and regarding *Race for Life* exclusively) female focused. Men are scarcely visible in breast cancer marketing resources, be those on- or off-line, in visual, audio or print media formats; thus, making it difficult for affected men to identify with the illness and the breast cancer community, while others fail to even recognise breast cancer as a potential threat to men’s health.

The feminisation and pinkification of breast cancer has undeniably served a purpose in developing a focus of attention on the illness. Not only that, it has built a community of women who have raised awareness and resources; and has multiple benefits for those women and potentially their significant others. Conversely, it has served to disadvantage men (and non-heteronormative women); gendering a cancer that affects both sexes to the extent that the disease in men is socially perceived as an oddity, so out-of-the-ordinary that for some it is nearly incomprehensible to consider it a concern for men’s health (Thompson & Kaye, 2013).

Current social constructions of breast cancer are incongruent with those of traditional masculinity; if breast cancer is gendered female, and being a man means not being like a woman (Kimmel, 1994 as cited in Hilton et al., 2009), to receive a breast cancer diagnosis is therefore ‘unmasculine’, and hence, identity crises and psychosocial distress in men can ensue.

To use Hughes and Wyatt’s (2015, p.1) phraseology, the “rise and sprawl” of the pink culture associated with breast cancer presents not only as a social movement but a political one too. Purposeful and profitable, the idea that purchasing pink goods goes some way to finding a ‘cure’ for cancer and specifically helps women in need is a marketable concept on an international scale, attracting human interest and consumerism alike (King, 2006; Sulik, 2011); something which marketers strive to preserve (Gibson, Lee & Crabb, 2014). Thus,
there is a continuing debate as to whether breast cancer in men (and non-heteronormative women) is inadvertently or intentionally overlooked at professional and political levels, simply because it is perceived to be less lucrative (Gibson et al., 2014). Yet, there is also the argument that the pink commercialisation of breast cancer has now become so commonplace in today’s society that it is hardly noticed anymore, and people miss the linkage with breast cancer awareness altogether (King, 2006). As Duggan (2006) commented in her review of King’s (2006, see cover page) book, titled ‘Pink Ribbons Inc: Breast Cancer and the Politics of Philanthropy’; what started as “organising for broad access to better health care is overshadowed by advertising and cause-marketing” resulting in personal, social and political costs. This further demonstrates why breast cancer presents as a critical health issue, especially breast cancer in men, and other minority groups whose access to breast cancer services was already narrowed.

2.5 Research aims and questions

Research – particularly psychosocial research – exploring men’s breast cancer experiences and life beyond the illness event exists (e.g. Hunt et al., 2011; Sime, 2012; Halls 2013; Ackroyd, 2016) but remains limited; consequently, so does adequate understanding about the disease in men, and the requirements – clinically and socially – of this underacknowledged minority patient group. As mentioned earlier in Chapter 1, this coupled with the burgeoning interest in men’s health and health inequalities, provides clear rationale for exploring breast cancer in men and the issues with which they contend further.

The key aims of this research programme are to:

i) gain an in-depth and holistic understanding of how men experience breast cancer

ii) advance knowledge regarding men’s constructions and meaning-making of breast cancer and masculinities
iii) ‘give voice’ to what is currently an under-researched minority group

iv) offer recommendations for how to improve the treatment, care and support of future men who experience breast cancer

Primarily, the research asks: ‘How do men describe breast cancer and their experiences of the illness?’ though it also intends to address the following subsidiary questions:

- What are the main challenges of living as a man with breast cancer?
- How do men view themselves as a community of individuals with breast cancer?
- What do men want from breast cancer care and support?

These questions, situated within a critical health framework, are explored through concepts and theories relating to men’s health studies, including masculinities and embodiment (Buchbinder, 2013; Biricik & Hearn, 2009) and holistic psychosocial oncology (Baker et al., 2014; Thewes, Buton, Girgis & Pendlebury, 2004). This begins with an interrogation of the qualitative literature that has previously explored the experiences of men with breast cancer, through the process of a qualitative synthesis; which is presented in the chapter that follows (Chapter 3).
Chapter 3 – Qualitative synthesis

Having set the research scene in Chapter 1 and offered an overview and contextualisation in Chapter 2; in this third chapter, the first phase of the two-part inquiry is presented: a qualitative synthesis. Serving a dual purpose in this context, the qualitative synthesis acted as the main literature review for the research programme, but also intended to: establish what research on breast cancer in men already existed; which research methods had previously been employed; and who the participant groups and research audiences were. In addition to providing a comprehensive understanding of the extant qualitative literature, specifically, the outcomes of the qualitative synthesis were used to inform the second part of the current research; a new critical qualitative inquiry exploring men’s breast cancer experiences, which simultaneously looked to further understandings while addressing some of the shortcomings of earlier studies illuminated by this synthesis.

3.1 Purpose

A qualitative synthesis searches systematically for research on a chosen topic and draws the findings from individual studies together; often enabling new understandings of the data to emerge (Seers, 2012). In the context of men and breast cancer, this concentrated review of what is a small body of literature served to ensure that the research furthered existing knowledge rather than merely repeating what has gone before; allowing for fresh insights to be gained and helping to identify new ways of studying the research population, and particular avenues of interest. Though systematic reviews of quantitative data are well-established, by comparison, synthesising qualitative research is a newer approach, and methods are still developing (Seers, 2012). Thus, to the best of the researcher’s knowledge, the synthesis presented here is the first of its kind on the topic of men and breast cancer. Accordingly, an (earlier) adapted version of this synthesis was recently published in a social
science journal (see Quincey et al., 2016), demonstrating how its applications extend beyond the thesis to have both academic and real-world impact, insofar as serving to inform future breast cancer research and practices; this, in keeping with the critical health psychology approach that is employed here.

Specifically, the purpose of this interpretive qualitative synthesis was to consider existing accounts of men’s experiences of breast cancer and explore these from within a critical health psychology framework (Murray, 2015). Through explorations of the embodied experience, discursive landscape and social positioning of men with breast cancer at all stages of the illness, the synthesis illustrates how marginalisation of men with breast cancer poses a range of psychosocial and psychosexual difficulties for men, in addition to the challenge of diagnosis. Though coverage of breast cancer in men in existing literature is sparse, in a collective evaluation of earlier research, current knowledge is expanded and further insight is generated upon which to build further research, through this meta-ethnographic synthesis.

Meta-ethnography is a well-established method, widely advocated as a successful means by which to synthesise qualitative research (Britten, Campbell, Pope, Donovan, Morgan, & Pill, 2002; Campbell, Pound, Morgan, Daker-White, Britten, Pill, Yardley et al., 2011), especially experiential data, allowing for systematic examination of existing research, facilitating a higher level of analysis and fresh perspectives (Noblit & Hare, 1988). Allowing researchers to explore phenomena from the insider’s perspective, meta-ethnography is often chosen for research syntheses on health and illness-related experiences (Atkins, Lewin, Smith, Engel, Fretheim & Volmink, 2008; Röing & Sanner, 2015). Further, in the context of the current research, which is situated within a CHP framework (see Figure 2, Chapter 4), using a qualitative method to review the extant literature was more fitting than a quantitative
systematic review, as all elements of this inquiry were about representing voice rather than measuring variables.

3.2 Method

Noblit and Hare's (1988) approach to meta-ethnography served as the framework for the interpretive qualitative synthesis that is presented. This analytic approach is advocated as a successful means by which to synthesise qualitative research findings (Britten et al., 2002), particularly experiential data; allowing for systematic examination of the research studies being considered, thus having the propensity to offer further insight and fresh perspectives (Noblit & Hare, 1988). Adopting Noblit and Hare’s seven-step procedure, the synthesis process comprised the following phases (see Figure 1). Firstly, the research focus and core lines of enquiry were established in order to develop the synthesis question, i.e. ‘How do men describe breast cancer and their experience of the illness?’

Secondly, a literature search was conducted, according to specific criteria, identifying research studies for inclusion in the synthesis. No parameter was set for start date and the search took place initially over a 28-day period in April and May 2014 (Note: two additional articles were later identified and have since been added to the synthesis, hence the version of the synthesis presented here differs slightly to that which was published (Quincey et al., 2016). The databases selected included; British Library EThOS, CINAHL Plus with Full Text, E-Journals, MEDLINE, PsycARTICLES, PsycINFO, Science Direct and SCOPUS. Relevant search terms and Boolean operators were ‘men’ OR ‘male’ AND/WITH ‘breast cancer’ AND ‘experiences’. The All Text (TX) search parameter was also applied. Selection was limited to full-text English-language articles reporting qualitative research conducted with men.
Initial analysis involved careful reading and re-reading to identify core themes and concepts within each study, recognising contextual aspects governing the interpretations and explanations offered. To assist with comparing and merging outcomes from the studies, key methodological information as it was reported by the original authors (i.e. second-order interpretations, see Britten et al., 2002) was tabulated. Next, emergent similarities and differences were considered to determine conceptual relationships among studies. Phases five and six involved recognising reciprocal translations (Noblit & Hare, 1988); identifying key shared inferences emerging from the studies, gaining a deeper, comprehensive understanding of the research phenomenon from which a line of argument could be established and deliberated. Finally, findings are expressed in a written discussion of inferences drawn from the whole dataset and how the studies serve collectively to inform understanding of men’s accounts.

The synthesis is grounded in data reported by the studies’ original authors, assuming that the interpretive findings presented are a fair representation of the data. Noblit and Hare (1988) prescribed this approach of synthesising researchers’ interpretations, and later publications describe how these secondary interpretations inform the tertiary-level inferences and findings presented in the synthesis that go beyond those offered in the original studies (see Britten et al., 2002; Campbell et al., 2011).

### 3.3 Results

The search yielded 8,419 potential reports; 8,404 of those were discarded after removing duplicates and non-relevant articles. The remaining 15 studies were screened for inclusion by title and abstract, of which nine studies met the inclusion criteria (Figure 1). Studies were published from 2000-2016; involving 98 men with different populations and methodologies (Table 1). Four overarching meta-themes emerged each of which are divided into a series of
sub-headings, allowing for structured presentation and discussion of the synthesis findings. Quotation marks denote original participant quotes, and studies are referenced by the number that appears in Tables 1 and 2.
8419 identified through database searches:
British Library Ethos \((n=3)\); CINAHL Plus with Full Text \((n=23)\); E-Journals \((n=27)\); MEDLINE \((n=86)\);
PsycARTICLES \((n=17)\); PsycINFO \((n=41)\); Science Direct \((n=1539)\); SCOPUS \((n=6683)\)

8404 discarded
(Duplicates, female-specific and male-only cancer articles)

15 screened by title and abstract

10 full-text articles assessed for eligibility

Reference lists of remaining 8 articles checked for additional empirical research

9 studies included in qualitative synthesis
(7 single-method, 2 multi-method studies)

Figure 1. Synthesis search strategy and results
### Table 1. Individual Description for The Included Studies (k=9)

<table>
<thead>
<tr>
<th>Authors (Year)</th>
<th>Country Sample</th>
<th>Sample</th>
<th>Data collection</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pituskin et al., (2007)</td>
<td>Canada; n=20</td>
<td>BC patients, post radiotherapy and/or chemotherapy</td>
<td>Face-to-face, unstructured in-depth interviews</td>
<td>Narrative exploration (story development)</td>
</tr>
<tr>
<td>France et al., (2000)</td>
<td>UK; n= 6, n=15</td>
<td>n=5 UK; n=10 overseas provided contextual data</td>
<td>Face-to-face, unstructured interviews</td>
<td>Content analysis</td>
</tr>
<tr>
<td>Donovan &amp; Flynn (2007)</td>
<td>UK; n=11</td>
<td>n=6 men diagnosed and treated for BC</td>
<td>In-depth, semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Naymark (2006)</td>
<td>Australia; n=11</td>
<td></td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Williams et al., (2003)</td>
<td>UK; n=27</td>
<td>n=9: men with BC</td>
<td>Semi-structured Focus groups</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Sime (2012)*</td>
<td>UK; n=42</td>
<td>n=19 men with BC</td>
<td>Part narrative, part semi-structured interviews</td>
<td>Framework analysis</td>
</tr>
<tr>
<td>Halls (2013)</td>
<td>UK; n=7</td>
<td>n=3 men with a history of BC</td>
<td>Semi-structured interviews</td>
<td>Discourse and content analysis</td>
</tr>
<tr>
<td>Hunt et al., (2011)*</td>
<td>UK; n=33 (*19 of which were recruited by Sime 2012 and feature in both studies) men recovered, recovering or still going through treatment</td>
<td></td>
<td>Semi-structured interviews via Skype</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Ackroyd (2016)</td>
<td>US; n=6</td>
<td>men diagnosed with BC in last 5 years. men receiving palliative care excluded</td>
<td></td>
<td>Interpretative Phenomenological Analysis</td>
</tr>
</tbody>
</table>

**Abbr.** BC=Breast cancer. BCC=Breast cancer Care. UK=United Kingdom
<table>
<thead>
<tr>
<th></th>
<th>Table 2. Core Themes from Each of The Included Studies (k=9).</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pituskin et al., (2007)</td>
</tr>
<tr>
<td>2</td>
<td>France et al., (2000)</td>
</tr>
<tr>
<td>3</td>
<td>Donovan &amp; Flynn (2007)</td>
</tr>
<tr>
<td>4</td>
<td>Naymark (2006)</td>
</tr>
<tr>
<td>5</td>
<td>Williams et al., (2003)</td>
</tr>
<tr>
<td>6</td>
<td>Sime (2012)</td>
</tr>
<tr>
<td>7</td>
<td>Halls (2013)</td>
</tr>
<tr>
<td>8</td>
<td>Hunt et al., (2011)</td>
</tr>
<tr>
<td>9</td>
<td>Ackroyd (2016)</td>
</tr>
<tr>
<td><strong>1.</strong> Poor awareness of BC in men</td>
<td><strong>2.</strong> Delay in diagnosis</td>
</tr>
<tr>
<td><strong>2.</strong> Problems gaining attention of doctor</td>
<td><strong>2.</strong> Shock – reaction to diagnosis</td>
</tr>
<tr>
<td><strong>3.</strong> Concerns with disclosure</td>
<td><strong>2.</strong> Stigma – attitudes to MBC</td>
</tr>
<tr>
<td><strong>4.</strong> Willingness to seek support from groups or other men</td>
<td><strong>2.</strong> Body image</td>
</tr>
<tr>
<td><strong>5.</strong> Lack of information</td>
<td><strong>2.</strong> Causal factors</td>
</tr>
<tr>
<td><strong>6.</strong> Negative body image</td>
<td><strong>2.</strong> Provision of information</td>
</tr>
<tr>
<td><strong>7.</strong> Felt life improved</td>
<td><strong>2.</strong> Emotional support</td>
</tr>
<tr>
<td><strong>8.</strong> Helping other men</td>
<td><strong>2.</strong> Poor awareness of BC in men</td>
</tr>
<tr>
<td><strong>9.</strong> Diagnosis</td>
<td><strong>2.</strong> Disclosure and knowledge of BC in men</td>
</tr>
<tr>
<td><strong>10.</strong> Contested masculinity</td>
<td><strong>3.</strong> Diagnosis</td>
</tr>
<tr>
<td><strong>11.</strong> Masculinity as a hindrance to men accessing health services and seeking medical consultation</td>
<td><strong>3.</strong> Disclosure</td>
</tr>
<tr>
<td><strong>12.</strong> Site of diagnosis</td>
<td><strong>3.</strong> Support</td>
</tr>
<tr>
<td><strong>13.</strong> Diagnosis – shock, confusion and despair</td>
<td><strong>3.</strong> Gender-specific information</td>
</tr>
<tr>
<td><strong>14.</strong> Interactions with health services</td>
<td><strong>3.</strong> Poor awareness of BC in men</td>
</tr>
<tr>
<td><strong>15.</strong> Dissatisfaction with support services and information</td>
<td><strong>3.</strong> Disclosure practices</td>
</tr>
<tr>
<td><strong>16.</strong> Limited choice for treatment</td>
<td><strong>3.</strong> Help-seeking strategy</td>
</tr>
<tr>
<td><strong>17.</strong> Limited sources of support</td>
<td><strong>3.</strong> Information and support</td>
</tr>
<tr>
<td><strong>18.</strong> Role of significant other(s)</td>
<td><strong>3.</strong> Discovery of BC in men</td>
</tr>
<tr>
<td><strong>19.</strong> Renegotiated masculine identity</td>
<td><strong>3.</strong> Treatments and their effects</td>
</tr>
<tr>
<td><strong>20.</strong> Pink Ribbon culture</td>
<td><strong>3.</strong> Challenged masculinity or male identity</td>
</tr>
<tr>
<td><strong>21.</strong> Felt life improved</td>
<td><strong>3.</strong> Information and support</td>
</tr>
<tr>
<td><strong>22.</strong> Helping other men</td>
<td><strong>3.</strong> Awareness of breast cancer in men</td>
</tr>
<tr>
<td><strong>23.</strong> Life with it</td>
<td><strong>4.</strong> Discovery with information and support</td>
</tr>
<tr>
<td><strong>24.</strong> Derailment due to my illegitimate illness</td>
<td><strong>5.</strong> Being in the shadow of pink</td>
</tr>
<tr>
<td><strong>25.</strong> Diagnosis</td>
<td><strong>5.</strong> Altered body</td>
</tr>
<tr>
<td><strong>26.</strong> Seeking certainty and control</td>
<td><strong>5.</strong> Odd man out</td>
</tr>
<tr>
<td><strong>27.</strong> Pink Ribbon culture</td>
<td><strong>5.</strong> The second sex</td>
</tr>
<tr>
<td><strong>28.</strong> Finding value in suffering</td>
<td><strong>5.</strong> Awareness of own mortality</td>
</tr>
<tr>
<td><strong>29.</strong> Discovering my mission</td>
<td><strong>5.</strong> Yesterdays gone</td>
</tr>
</tbody>
</table>

3.4 Negotiating the complexities of diagnosis and disclosure

This first meta-theme describes initial help-seeking practices and disclosure strategies following diagnosis.

3.4.1 Delay, disbelief and disarray surrounding diagnosis

Participants described seeking help throughout diagnosis as a complex process. Prior to their own illness experience, most had little-to-no knowledge of breast cancer in men (1,2,4,6,7,8), and many felt that health professionals also lacked relevant knowledge (1,3,4). Participants generally reported seeking medical help promptly on discovering symptoms (1,2,5,6), though some did delay, either because they did not recognise their symptoms as a sign of breast cancer (8,9), and/or because their symptoms did not cause discomfort or affect daily life (2). Commonly, multiple consultations were necessary before the men’s symptoms were ‘taken seriously’. Some voiced frustrations and/or regret at not being able to access care sooner (1,2) and recognised the disarray that pursuing a diagnosis caused (8). A confirmed diagnosis generally disrupted the men’s worlds further. Most expressed ‘shock’, ‘surprise’ or ‘disbelief’ at being diagnosed with breast cancer (1,2,3,4,7,8,9), a response commonly mirrored in the reactions of significant others and some healthcare professionals. Shock reactions were greater among those who felt healthy (8) and participants used words like ‘bewilderment’, ‘disorienting’ and ‘confusing’ when describing their lived experiences. One man declared feeling ‘stupid’ for not having considered that he might have breast cancer (7).

Diagnoses were delivered factually with little consideration for any psychological impact. Thus, most men adjusted to their cancer without professional psychosocial support. For the majority, formal diagnosis compounded feelings of disarray, but a small number of the men said knowing was a relief (8).
3.4.2 ‘Coming out’ as a man with breast cancer

Self-disclosure as a man with breast cancer was an idiosyncratic process. The men were selective about who they disclosed to, adopting a range of strategies. ‘Strategic announcing’ (6) was common, with most participants disclosing their breast cancer on a ‘need-to-know basis’, initially only to immediate family and close friends. Some of the men likened the process to ‘coming out’ (3,7), positioning breast cancer in men as a taboo-like illness. Many questioned the social acceptability of men developing breast cancer and were concerned about disclosure due to the ‘unusuality’ (6) of the illness in men, and how it might impact on others (1,3,4,8). Some participants felt embarrassed to say they had breast cancer, concerned that it might make others ‘feel uncomfortable’ (8). Despite such concerns, for most participants, maintaining complete secrecy was neither practicable nor preferable, and some said they ‘should not need to keep it secret’ (8). Though some found a period of concealment provided them with relief and time to reflect (3), others described hiding their breast cancer diagnosis as ‘burdening’ and ‘distressing’ (6), and said it was ‘easier if people knew’ (8). Privacy and discretion regarding the diagnosis was a dominant concept, however, some participants did report feeling compelled to publicise their breast cancer, duty-bound to ‘spread the word’ about breast cancer in men (1,4,6,7,8,9).

3.4.3 The significance of others

Almost all participants showed concern for others; how they would react and respond to the diagnosis, and how it might affect their lives. Many identified the key role of their wives (1,2,5,6,8), with several attributing their survivorship to the proactive behaviours of partners pre-diagnosis, explicitly, in seeking medical attention, and thus formal diagnosis (2,5). Support offered by significant others included assistance with disclosure and managing practical and financial matters. Several participants commented on role changes brought
about by their illness (1,2,6), as well as the impact on close relationships and the need to form ‘adapted relationships’ with loved ones, owing to the physical and emotional strains of living with breast cancer (1,6). Despite disruptions to sexual and psychological well-being, the majority maintained close spousal relationships, some reporting an improved closeness between them and their partners (1,6), asserting that the experience, despite the difficulties, had changed their lives for the better (1,9). Few of the men appeared to lack familial support; only a couple said they managed their breast cancer experience single-handedly (8).

3.5 Navigating multiple layers of marginalisation

The second meta-theme focuses upon the ignorance, imbalances and stigma surrounding breast cancer in men.

3.5.1 ‘No protocol’ for male patients

Participants mentioned consistently that there was no modus operandi regarding the management of men with breast cancer, claiming that difficulties encountered resulted from there being ‘no protocol’ for the care and support of men (4,9); particularly provisions for psychological support. Generally, participants were satisfied with their medical care, but discontent that no specific clinical arrangements existed for the treatment and aftercare of men. The men were often told that they would be treated according to the methods prescribed for treating women, because the clinicians ‘knew no other way’ (2,4,6,9). Despite receiving the same treatment, many participants did not consider that men and women were cared for equally. Some felt that their queries and concerns, particularly those regarding treatment and side-effects, were left unanswered (1,3,4,6,8). Some described how health professionals acknowledged their inexperience in caring for men with breast cancer; typically having ‘no case reference’ with which to draw comparisons (4,9). Participants expressed the negative
effect of such uncertainty (9), and how the ambivalence expressed by health professionals strengthened men’s feelings of illegitimacy as breast cancer patients (9).

3.5.2 Informational resources ‘lack relevance’

Generally, the men received few resources specific to men. Much of the information was women-focused, referring to, for example, post-mastectomy brassieres and breast reconstruction. Participants implied that available literature was excluding, and they were disappointed by the paucity of information regarding a man’s perspective, feeling that men were under-represented in patient information resources. One man questioned, ‘Where’s my voice?’ (8). Some also felt ill-informed about possible side effects of treatments prescribed (2,3,6,8). How much information the men wanted, and at what stage, varied (8,9). Many participants chose not to read the printed resources offered to them, instead acquiring knowledge via the internet: ‘the first thing you do is Google it’ (8). Some talked with friends (women) ‘in the know’ and noted information from their wives; many of whom had researched breast cancer in men on behalf of their husbands (2,6,8).

Although most participants argued that breast cancer information needed improvement to make it inclusive, when asked about men’s informational needs, many did not want separate resources, but preferred identifiable areas within existing materials (1,2,5,7), with perhaps the inclusion of pre/post-surgery photographs (5).

3.5.3 Limited choices and opportunities

The notion that men with breast cancer are not afforded the same choices and opportunities as women was highlighted throughout the literature, with the men’s accounts offering several examples of active marginalisation. Generally, participants recounted having little input in treatment decision-making (1,4,6,8). Mostly, a specific course of treatment was prescribed and alternative treatments never discussed, though the men presumed that women were
offered a choice of treatments (6). Responses concerning the men’s preferences about involvement were mixed. One or two would have preferred more autonomy regarding treatment-related decisions, but the majority accepted clinicians' choices and were content to ‘take a backseat’ (4,6,9). A small number considered that they received inferior treatment compared to women, blaming this on their own behaviour and ignorance (4,6), although one man thought that he received greater care being a ‘lone soldier’ amid an all-women unit (6), and another said he was given ‘special treatment’ (8).

Participants also identified gender discrepancies in post-surgery care, support and research. One noted that women were afforded decorative carry-cases for postoperative surgical drains, whereas men received carrier bags (6). Others were excluded from clinical research trials, because they were men (6,8). Several participants claimed that clinicians tried to conceal them from women in waiting areas and wards, purposefully segregating them to assuage discomfort for women (3,6,8), perhaps denying them peer support and/or the benefits of sharing experiences. One man was advised that placing him on the breast care ward might embarrass other in-patients (8).

The men’s accounts also revealed inconsistencies in the care provided between the men (2,5,6). While some met with a breast cancer nurse, others did not; some were informed about support groups and acquainted with other men (patient-survivors), but few received the same opportunities. However, participants usually did not want to attend organised support groups or engage in formalised therapies (1,2,4,5,6,8).

3.5.4 Breast cancer is ‘worse for women’

The consensus among the men was that breast cancer has greater significance for women and a lesser impact on men. Self-marginalisation was identified as a recurrent phenomenon within the accounts, with participants consistently downplaying breast cancer in men, positioning
women as more ‘important’ and ‘deserving’ of optimal care and support (2,4,6); ‘men are the minority, and shouldn’t be banging their drum too much...’ (7). When referring to breast cancer in women, the men’s language was more emotive. Many commented that having a mastectomy ‘means more’ to women (4,6,7,8); one man remarked that losing a breast was ‘much more traumatic’ for women than men (6), while another affirmed, ‘for me as a man losing my breast isn’t...a major problem’ (7). The majority of men conceded that the rarity of breast cancer in men compared with women had led to the development of women-focused practices and dedicated services. Many said it was important not to ‘impose’ on services for women: ‘I didn’t want to be a nuisance’ (4,8,9). Most were reverent towards women and frequently articulated that women should receive optimal care and support ahead of men, given the ratio of women to men diagnosed (4,6). However, this view contradicts the men’s ambitions to reduce the marginalisation of men with breast cancer.

3.6 Re-establishing masculinities

This meta-theme reflects on the centrality of gender and the need for men to renegotiate their masculine identities.

3.6.1 The ‘paradoxical gendering’ of breast cancer

Almost all of the men described breast cancer as a ‘female illness’. Several participants felt that the social acceptance of breast cancer hinges on the disease presenting in women (4), though some noted that it was the same disease in women and men (8). The constructed feminine identity of breast cancer seemingly had negative implications for the men (3,6,9), most feeling that developing breast cancer challenged their masculinity and influenced how others appraised their manliness and/or sexual orientation (1,2,3,6,7,8,9). Some commented that living with breast cancer was ‘unsettling’ since it challenged embedded ideas pertaining
to gender and conceptions of being a ‘real man’ (3,6,9). The men proclaimed their masculine credentials using phrases such as ‘regular guy’ in their self-descriptions (3), and many struggled to connect with the word ‘breast’ given its associations with the female body. Some described the disease as ‘chest cancer’ to de-feminise the illness (1,6,8), however others said this terminology was ‘confusing’ and ‘unhelpful’ (8).

Many participants questioned why they had developed breast cancer rather than an illness that had ‘something to do with men’ (1,3,4). Some regarded it as a personal failing or ‘individual defect’; while one participant considered it ‘contamination by femininity’ (2,3). Another described their breast cancer as ‘the enemy within’, stating it was essential to ‘engage with the enemy’ in order to reaffirm his masculine status (3). Participants with a better work-life balance and fewer financial strains pre-diagnosis expressed greater psychological adjustment to illness and appeared to be more successful at renegotiating their masculinities (1,2,6,7). For those unable to re-establish their identities successfully, feelings of being perceived to be a ‘lesser man’ were compounded and poorer coping was reported.

3.6.2 Mistaken identities of men with breast cancer

The men described how their gender was often mistaken in clinical settings, outlining instances of being referred to as ‘Mrs’ or ‘she’ when staff called out their name (6). Some participants were assumed to be chaperones to female patients (7,8), rather than bona-fide breast cancer patients: ‘I was sure all the women in the breast centre thought I was supporting my wife’ (7). Similar experiences were also noted when collecting their Tamoxifen – anti-estrogenic hormone therapy – prescriptions, with some of the men reporting that pharmacists were reluctant to issue the medication (8). The men struggled to identify with being a breast cancer patient; one preferring to think of fantastical reasons for presenting at the breast clinic, imagining himself as the doctor rather than the patient (6).
Some of the men remarked how their diagnosis led people to presume them non-heterosexual, or regard them as being ‘half-woman’, since ‘real men do not develop breast cancer’ (3). Age-related assumptions also affected participants’ illness experience. Commonly, younger participants said they had to persist to get their symptoms noticed (1,2,8). Several said their breast cancer would have been detected sooner had clinicians not assumed them to be too young to develop the disease (1,6,7).

3.6.3 Embodiment of breast cancer in men

Participants discussed learning to live with their changed embodied self over time, acknowledging that it took time to adjust to their altered appearance post-treatment (2,4,6,8,9). For most, their body symbolised their manliness and comments concerning the impact regarding post-mastectomy scarring on their body image were mixed. Commonly, participants felt their scarring brought a ‘permanent stigma’ that caused them to feel ‘embarrassed’ and ‘less attractive’; yet, some were explicitly ‘proud’ of their body, and said their scarring was ‘not something to be ashamed of’, but, a mark of cancer survivorship (1). ‘Feeling well’ was generally more important to the men than worrying about post-surgery scars (6) but many said that their scars made them feel ‘self-conscious’, ‘down’ and ‘ill at ease’ about their physical appearance and some found it difficult to view and touch their scarring (4,6,8). Several felt it necessary to conceal the reality of their changed body from others to ‘save embarrassment’ and deter uninvited questions (5). This included hiding scarring with clothing, avoiding social situations where men would ordinarily be bare-chested, e.g., sunbathing or swimming (1,4,5,8), and telling stories about their ‘war wounds’ (6); preferring to exercise these protective practices rather than divulge their breast cancer.
3.7 Moving past pinkification and into ‘the blue’

This meta-theme focuses on future approaches to and the management of men with breast cancer.

3.7.1 No man’s land: entering unknown territory

Another recurring theme was the notion that breast cancer in men was ‘unknown territory’ for all concerned. Commonly, men felt ‘out-of-place’ as a man with breast cancer (9), especially when attending clinics, which were typically focused on women’s health (6). Only one man mentioned his hospital's plans to set up a clinic specifically for men (8). Professionals’ referring to the men as, ‘special cases’ (6) was an unwelcomed label that reinforced feelings of disparity and alienation. Participants generally concurred that regarding breast cancer in men as an ‘oddity’ needed changing at every level (9). Many suggested re-educating both laypersons and health professionals about breast cancer (5,6); particularly in terms of disease manifestation and at-risk individuals, including reworking breast cancer campaigns (1,7) to raise awareness about the illness in men.

3.7.2 More than just a pink ribbon

Participants were acutely conscious of the feminine connotations, and continually referred to widespread gendered approaches towards breast cancer (9). One commented: ‘everything for breast cancer was for women’ (6). Many highlighted the ramifications that pinkification of the disease had: in disregarding breast cancer in men, delaying illness detection and generating deficits in support. One man commented ‘...it’s like swimming against a tide of pink’ (7), while another described ‘living in the shadow of pink’ (9). The majority were keen to raise the profile of breast cancer in men and to move beyond current feminised representations. Most were aware of the risk of breast cancer in women, but unaware of risks
to men prior to their own illness. The consensus among men was that existing breast cancer campaigns were misrepresentative and compounded ideas that the disease is a women-only concern. One man remarked, ‘Men are only made aware of testicular or prostate cancer, never breast’ (4), while another said that breast cancer in men remained ‘invisible’ in terms of disease awareness (6,9). Many said that use of the pink ribbon, symbolising breast cancer despite most men and many women being unable to identify with the ‘girly’ icon, should be reconsidered (6,7) (see Sulik, 2011).

3.7.3 Minor changes of major importance

All participants remarked on the need to improve experiences for men with a desire for subtle refinement of existing practices and preferences over radical changes. Supplementary information relevant to men alongside women was favoured over gender-distinct care packages (1,4,5,7,9). Inclusion and recognition were recurrent themes regarding the men’s thoughts about care and irrespective of whether men choose to participate, the majority said men should have the opportunity to attend support groups and engage with other patients, highlighting the importance of feeling included. Many considered that it would have been beneficial to interact with other men (patient-survivors) (1,4,5,8) and said this would be advantageous for future patients.

3.8 Discussion

Drawing on the findings of nine experiential studies exploring 98 accounts of men’s experiences of breast cancer in Western contexts, this qualitative synthesis has exposed the constrained and gendered framework within which breast cancer is currently understood in Western societies. The themes illuminate the particular difficulties encountered by men with breast cancer; showing that gendering of breast cancer is apparent at all levels and unequivocally marginalises men at every stage of the illness trajectory. In addition to external
stigma, self-marginalisation is also evident, with the men apparently engaging in self-denigration, viewing men with breast cancer as encroaching on women’s territory. The discussion that follows critically considers how men recounted their experiences, highlighting key influences and presenting ideas for the future of breast cancer care and research.

3.8.1 Breast cancer’s inconsistency with hegemonic masculinity

The men’s own descriptions of breast cancer represented lay conceptualisations and social representations about both the disease and gender. Evidently, lay understandings of breast cancer and traditional masculinity are dissonant, hence the men’s feelings of illegitimacy and incongruity when receiving a breast cancer diagnosis. Pinkification of the disease undoubtedly influenced the men’s breast cancer experiences, with the permeating ‘pink ribbon culture’ having clear ramifications. The expectation that breast removal would be meaningless for men coincides with gendered conceptions about the human breast in Western societies (Williams et al., 2014). However, living with a changed body presented unexpected psychosocial and psychosexual challenges for many men, including the establishment of adapted selves, behaviours and relationships thought necessary for improved coping and outcomes.

As Williams and colleagues (2014) explained, and as discussed earlier in Chapter 2, as a power construction, gender inequality interacts with other systems of inequity, including sexuality and age as exemplified in some of the men’s accounts, demonstrating the tendency for people to make assumptions based on these constructions. Power relations were repeatedly discussed, with the men considering their position relative to both women and other men. The men consistently compared their breast cancer experiences with women’s, continually articulating the illness as ‘worse for women’, ‘less significant’ and ‘meaningful’ for men; actively positioning women as victims, possibly as a means of affirming their
dominant hierarchical position and re-establishing their masculinity (see Connell, 1995). The men generally accepted discrepancies between men and women; however, where inconsistencies in treatment and care were recognised between men and other men, some displayed disillusionment. It can be argued that the lay perception that the breast cancer experience has a greater impact on women encourages men to outwardly maintain this idea; to protect their gender identity and resist emasculation. Further, men’s downplaying of the severity of their breast cancer serves doubly as a coping mechanism, allowing for improved psychological adjustment to illness.

3.8.2 The combined impact of ‘self’ and ‘other’ stigma

Enacted and felt stigmas (Scrambler, 2004) were both exemplified in the men’s accounts, and clearly impact on the men’s illness experience. Stigma is a power structure which is the “co-occurrence of its components” and includes aspects like stereotyping, segregation, loss of status and discrimination (Link & Phelan, 2001, p.363). If the marginalisation of men with breast cancer is concurrent with these ‘components’ as suggested, then men themselves are contributing to this by positioning women with breast cancer as more ‘important’ and ‘deserving’ which can be considered a protective practice. However, it also reinforces the disparity, perpetuating the stereotype that breast cancer is merely about women, adding to the men’s feelings of ‘isolation’ and ‘illegitimacy’. Adopting a nonchalant approach may also lead health professionals to assume men are content with the current favouring of women.

Men were acutely conscious of the impact of other-stigma on men’s breast cancer experiences; however, their awareness of the effects of self-stigma on their illness experience is more questionable. Many men said that they were consistently denied opportunities and choice throughout their illness, but few recognised that they had denied themselves opportunities too through their own behaviours; for instance, in refusing to read patient
resources, failing to query treatment-related decisions, and rejecting formal support services. Based on these findings, it is proposed that efforts to reduce both other- and self-stigma are necessary to target sources of such marginalisation.

3.8.3 Men and women’s breast cancer accounts: similarities and qualitative differences

Several studies exist which compare breast cancer in men and women, however, most focus on biomedical rather than psychosocial aspects (e.g., Anderson, Jatoi, Tse & Rosenberg, 2010), and there is little empirical research which systematically explore similarities and differences in men and women’s accounts. This synthesis, in accordance with the premises of the thesis as a whole, focused explicitly on men’s breast cancer experiences without simultaneous analysis of women’s accounts, but comparisons can be made with previous syntheses exploring breast cancer in women (e.g., Howard, Balneaves & Bottorff, 2007; Jones, Maben, Lucas, Davis, Jack & Ream, 2015).

Some shared behaviours present in men and women’s accounts including, a process of self-questioning and blame upon diagnosis (Gibson, Lee & Crabb, 2014). However, other behaviours and the underlying motivations behind these often appear to be considerably or subtly different. For example, regarding disclosure practices, strategic announcing is common in both sexes, yet often exercised for different reasons. In women, this serves to protect significant others from their illness and preserve aspects of the self, such as professional status, which disclosure has the propensity to threaten (Hilton, Emslie, Hunt, Chapple & Ziebland, 2009). For the men however, it permits normalcy and an initial maintenance of privacy whilst they come to terms with their condition. Subsequently, as previously noted, a significant number of participants across several studies later became active in raising awareness of breast cancer in men through publicising their own stories.
The use of military language and war metaphors is also evident across accounts. Women tend to use such language prospectively, motivating survival of breast cancer and overcoming the war on their bodies (Garrison, 2007); however, the men’s usage was often retrospective, related to the changed embodied self and re-establishment of masculine identities, e.g., ‘lone soldier’, ‘war wounds’. That almost all of the men were disinclined to engage with support groups may also represent a common difference between men and women with breast cancer. As Moynihan (2002) points out, unlike women, men are not socialised to seek support, and being emotionally expressive is synonymously feminine. If being a man means not being like a woman (Kimmel, 1994) then men who adhere to traditional hegemonic masculinities are unlikely to adopt coping practices labelled as feminine. The men feared being perceived differently from other men, however, from a hierarchical perspective, it could be argued that they also fear being perceived to be the same as women. Gender constraints could therefore be governing patient-survivors’ motivations and breast cancer behaviours.

3.8.4 Going forward: future orientations for breast cancer in men

The men’s desire for change regarding the management of men with breast cancer is evident in their discussions about current practices and hopes for the future. As research has previously implied (e.g., Al Naggar & Al Naggar, 2012), the synthesis revealed that knowledge and awareness about breast cancer and breast health in men is poor in lay populations and limited among health professionals. To reduce the feelings of ‘shock’ and ‘disbelief’ that many men reported, increased advocacy and activism is recommended. However, changing embedded social constructions about breast cancer is likely to take time, and requires concerted efforts at every level.

Many participants had clear ideas about engendering and implementing change in breast cancer care for men. Re-educating both public and professionals about breast cancer
presented as a primary objective, yet, the men typically advocated understated changes to patient resources rather than radical reinventions. Inclusion rather than coercion is evidently paramount to encouraging men to seek professional care and support yet, in accordance with earlier findings (e.g., Iredale et al., 2006), most men stated no desire to utilise support services. However, knowing that such services were available and accessible to men could foster men’s sense of belonging. Presenting men with opportunities, choice and a degree of autonomy in treatment-related decision-making would likely have an empowering influence too, regardless of whether this agency is exercised. Simply redressing clinical settings and services to appear more gender and culturally neutral may help to reduce the feelings of alienation and disequilibrium that some of the men experienced.

The paucity of experiential research into breast cancer in men, plus the apparent exclusion of men from clinical studies clearly contributes to the marginalisation of men with breast cancer and demonstrates a need for further research; hence why the second part of this research programme focused explicitly on giving voice to men who had experienced breast cancer. This synthesis reinforces the importance of engaging men with health research, particularly regarding changing gender-based health inequities and giving voice to minority groups (Barker, Ricardo & Nascimento, 2007). Giving voice to men with breast cancer is multipurpose: not only can this enrich phenomenological understandings of the disease in men; it also emancipates these men, helping them to re-establish their masculinities, identities and sense of self. Informed by the outcomes of this synthesis, the second study phase looked to address some of the identified shortcomings of earlier inquiries, and further, to expand the current knowledge base by adopting an alternative approach to those previously employed to study men’s breast cancer experiences.
As reflected in the language men used to describe breast cancer, current approaches towards the illness are clearly influential in shaping related ideologies, both public and private. The notion that breast cancer is feminine and pink has become an embedded social construct; one which findings indicate requires modification if constructions of, and perspectives towards, breast cancer are to change. However, as many contemporary theorists note, reversing the pinkification of breast cancer presents as a complex challenge. Many argue that the pink ribbon culture surrounding breast cancer is not merely happenstance; it is a purposeful, political and profitable approach with a multifaceted nature (Sulik, 2011, see Chapter 2, 2.4). Critics argue that breast cancer philanthropy is often strategic and helping others, especially vulnerable women, is a marketable concept attracting human interest and consumerism alike (King, 2006, see Chapter 2, 2.4). It could therefore be argued that dissonant voices do not fit with such representations, and as such, men (and feminist and/or lesbian women) are inadvertently or intentionally overlooked at expert and political levels in order to preserve the consumerism generated by the pink ribbon culture (Gibson et al., 2014, see Chapter 2, 2.4).

Indeed, research has shown that along with men, many women would also welcome change regarding breast cancer culture (Kaiser, 2008). If the wider patient collective is unable to identify with the existing pink ribbon culture then, as Sulik (2011) previously advised, breast cancer researchers and health promoters should re-assess the use of both the colour pink and the emblematic ribbon. Evidently, the un-gendering of breast cancer potentially has numerous benefits for both men and women. However, little consideration has been given as to how this ‘un-gendering’ and more diverse and inclusive representations of breast cancer might affect those women who do identify with the current culture, and also financial contributions to research and support services, presenting a possible future line of enquiry for breast cancer researchers. This is discussed further in Chapter 9 (9.6).
3.9 Limitations

A number of limitations salient to the current review are identified. First, the dearth of literature on the topic yielded very few studies eligible for inclusion, therefore, constraining the interpretations regarding men’s accounts. Second, methodological differences in the studies may have influenced interpretations. Significant differences can exist between accounts yielded through focus groups and one-to-one interviews (Gill, Stewart, Treasure & Chadwick, 2008). In the case of all but one paper (5) the data were gathered in a single session and may therefore reflect only the men’s most immediate concerns. Further, not all studies had an exclusively men-only sample, some gathered data from women (5,6,7), health professionals (4,5), and staff members of charitable organisations (7) too, which may have influenced the original interpretations of men’s accounts on which this synthesis is based. In producing this analysis, the researcher, when working with these papers, tried to work exclusively with material provided by men with breast cancer themselves. Third, whilst participants in the studies were sampled from a variety of clinical and community contexts, few papers provided information about the ethnic background of the participants, and of those that did (6,8), participants were disproportionately white. The papers adopt a heteronormative approach with little inclusion of gay or unmarried heterosexual men and consideration of how other social differences such as social class or disability may interface with experiences of cancer and healthcare. The researcher is thus cautious of making claims for transferability to more diverse populations and is aware that issues around stigma and marginalisation may have been overly simplified for some men with breast cancer who already experience institutional discrimination within healthcare services based on, for example, ethnicity and sexuality. Finally, as some of the synthesised articles were published in close succession (2003-2007, and 2011-2013), synthesis may represent only a snapshot perspective of men’s lived experiences of breast cancer captured at a particular point in time. Changes made to
policies, practices and the medical management of men since these articles were published is underreported, and the limited amount of research available precludes systematic comparisons over time. Furthermore, as this synthesis did not allow for comparisons with men’s experiences of other reproductive cancers (e.g., penile, prostate and testicular), it may be beneficial for future research to establish which of the findings reported are specific to breast cancer.

Identifying these limitations profoundly influenced the second part of the research programme, which intended to remedy some of these issues; affecting the design and approach of the study, i.e. the decision to employ two data collection methods, and also influencing recruitment and sampling strategies, e.g. efforts to involve BAME men, and men from other minority communities.

3.10 Conclusions and final recommendations

This synthesis has demonstrated how men diagnosed with breast cancer navigate a series of biomedical, psychosocial and socio-political challenges, some of which are unique and some shared by other individuals with (breast) cancer. In particular, it has highlighted how men often expect and receive suboptimal care, and how in downplaying their concerns and distancing themselves from certain coping resources, they protect their masculinities but further remove themselves from both appropriate recognition and key resources of care and support.

Current approaches to breast cancer care and advocacy marginalise men, and action is required at all levels if these gender inequities are to be successfully confronted. Health promoters and professionals need to move beyond pinkification and ‘into the blue’, by including a wider range of men in breast cancer campaigns, and in reviewing screening, treatment and aftercare. Development and subsequent assessment of specific interventions are
necessary to change the women-focused ideologies and attitudes currently held about breast cancer, and to improve advocacy and activism for/by men. Future use of the pink ribbon in association with breast cancer also needs careful consideration if awareness-raising campaigns are to reach out effectively to all concerned. Further, the synthesis highlights the need to develop related research using a more nuanced and sophisticated range of methodologies around men with breast cancer, e.g. Photovoice (Morrison & Thomas, 2015), and especially with samples that include men from different social backgrounds and cultural contexts, suggesting this is essential to improving understanding men’s needs; hence the employment of an integrated methodological approach for the second study phase, which also aimed to recruit men from diverse communities.

3.11 Chapter summary

The above synthesis demonstrates clear scope for further research exploring the lived breast cancer experience in men, and factors which serve to influence these men’s experiences; including the role of masculinities, pink culture and issues surrounding breast cancer inequities. To date, there has been little expansion regarding the lines of inquiry qualitative researchers have investigated in relation to men and breast cancer, or indeed with regards to the methodologies they have employed. Further, a number of the studies lacked, or lacked reference to, clear theoretical grounding in their analyses. Nevertheless, the studies each have their individual merits and collectively provide some insight into what remains an under-researched, sometimes ill-informed illness in men. Together, they serve to illustrate the constrictive framework currently adopted by public and professionals to understand breast cancer in men, and arguably, men’s health more widely; indicating the need for a less rigid and more participant-centred approach going forward. With this in mind, the following Chapter (Chapter 4) introduces and justifies the methodology behind the second phase of this
current inquiry: a new multi-method exploration into men and breast cancer; developed in accordance with the findings of the qualitative synthesis, and which specifically aimed to address some the identified limitations of the extant literature in the field.
Chapter 4 – Methodology

As demonstrated through the qualitative synthesis presented in Chapter 3, few qualitative explorations of men’s breast cancer experiences currently exist, and of these, the majority have tended to employ traditional single-method data collection practices; typically interviews or focus groups, with analysis of the verbal data produced. To offer fresh insight and to expand on current understandings of men and breast cancer, in view of the qualitative synthesis findings, the second phase of this research adopted a multi-method approach; combining the collection and analysis of verbal and visual data. The decision, both to move beyond a mono-methodology to investigate men and breast cancer, and to incorporate visual representations alongside verbal accounts, was multifaceted; as the current chapter and Chapter 5 work together to explain.

Here, the multi-methodological strategy employed is introduced, alongside discussion of the epistemological complexities of methodological pluralism, and explanation of the applicability of the chosen methodologies to the line of inquiry. As mentioned earlier in Chapters 1 and 2, several theoretical and methodological perspectives underpin this research, which has an interdisciplinary focus. How these nest within the superordinate critical health psychology framework informing this research, and interrelate, is illustrated in Figure 2.
Though principally informed by Critical Health Psychology (CHP; Marks, 2002) the research also draws on Critical Realism (see Willig, 2013), the tenets of Phenomenological Psychology (Smith, 1996), and some components of Participatory Research (PR; Cargo & Mercer, 2008); all of which share essential core concepts with CHP. It will be argued that this epistemological fusion and synergistic approach to the study of men and breast cancer is not only innovative, but appropriate and advantageous for gaining greater insight and a more comprehensive understanding of men’s breast cancer experiences. Ontological and epistemological considerations are presented first, followed by a discussion of the challenges and opportunities associated with integrating these competing perspectives, before outlining the methods of data collection and analysis.
4.1 Ontological and epistemological considerations

Before embarking on mixed/multi-methods research, it is essential that researchers are mindful and critical of the paradigmatic differences between methodological approaches (Sale, Lohfield & Brazil, 2002). The potential challenges of merging paradigms and integrating different research methodologies are typically discussed in regard to quantitative-qualitative combinations (Tariq & Woodman, 2013); yet similar concerns are also noted when mixing multiple qualitative methods that adhere to alternative paradigms (Chamberlain, Cain, Sheridan & Dupuis, 2011). Criticisms of mixed/multi-method research include that it is often adopted uncritically (Mayoh & Onwuegbuzie, 2015), and that researchers, particularly novice researchers, fail to adequately understand the epistemological bases of the methods employed; consequently, leading them to make illogical and unsupported claims (Giorgi, 2008b, Chamberlain, 2012). Nevertheless, methodological pluralism in qualitative research is possible, and combination of different qualitative methodologies and methods is currently in vogue (Barnes, Craddick, Clarke, Cromby, McDermott, Willis et al., 2014; Frost, Nolas, Gordon-Brooks, Esin, Holt, Medizadeh, et al., 2010). Even those which subscribe to different paradigms can coalesce, provided that integration is justifiable in view of the overarching philosophical foundations of the research (Willig, 2013). With that in mind, before the methodological strategy is discussed here, it is necessary to explain first the ontological and epistemological stances underlying this.

As mentioned above and in Chapters 1 (1.2) and 2 (2.1), the research is embedded theoretically and methodologically within a CHP framework; a contemporary critical scholar-activist approach within health psychology, concerned with promoting health and well-being, and challenging health injustices in view of the broader socio-political context and perceived need for health action (Murray, 2015). As Johnson (2012) notes, due to its broad scope and
diversity, a variety of different approaches hailing from disparate positions – ontologically and epistemologically – come under the CHP umbrella. CHP approaches are typically either action- or critique-based; hence the action/critique debate, which situates these positions as being either/or and diametrically opposed from one another (Johnson, 2012). Conceptual tensions between the two perspectives perhaps contravene the adoption of a pluralist critical health psychology that encompasses a variety of epistemologies (McVittie, 2006). However, action and critique are not absolute positions (Johnson, 2012), and it is important to recognise that the divergent paradigms and different epistemological perspectives that critical health psychologists adopt are not necessarily mutually exclusive (Willig, 2013). Contemporary critical health psychologists therefore advocate research approaches which seek to work with both action and critique and the tensions between them (Gergen & Zielke, 2006), moving towards developing an approach that is action-oriented, critically-informed and encourages reflexivity (Johnson, 2012).

The centrality of reflexivity in critical health and experiential qualitative psychologies is widely acknowledged (Shaw, 2010). A necessary yet complex undertaking, reflexivity is essential for understanding how researchers, the researched, and their interactions, influence the research scenario; from before the research idea is even formulated, through to gathering and analysing the data, and thinking about how the effects of disseminating their research in certain ways may affect the community being researched (Shaw, 2010; Langdridge, 2002). It is critical that the experiences of social beings are understood in terms of context, space, time, and consciousness; as Gadamer (1975) noted, researchers and participants each have their own presuppositions, beliefs and predilections for understanding phenomena with which they enter the research process, and which are influenced by engaging with the research. Understanding “other-ness” is therefore only possible through simultaneous self-interpretation accordingly (Finlay, 2003, p.108). Reflexivity is discussed again later in
Chapter 9, alongside presentation of the researcher’s reflections relative to the current inquiry (section 9.9).

In view of the critical health psychology framework adopted and the experiential nature of the research question(s) being asked, from an ontological perspective, the ‘reality’ of men’s breast cancer experiences is understood from a critical realist position; the reasons for which will now be considered.

**4.1.1 Critical realism**

Critical realism is a contemporary, intermediate philosophical position situated along the realist-relativist continuum, combining realist ambitions, e.g. to better understand the ‘real’ world, with relativist postulations, e.g. accepting the impossibility of direct access; and in conjunction with CHP its intention, as part of its activist principles, is to make real changes for people (Willig, 2013). It acknowledges that a knowable reality exists independently of theoretical assumptions and the human mind, irrespective of whether this ‘reality’ can be directly experienced or comprehended (Levers, 2013). Further, it accepts that *a priori* truths are formed about phenomena on the basis of partial access, and that description of the whole derives from fragmented glimpses which researchers consider and agree on (or reject) as being representative (Levers, 2013). Though what exists may be independent of descriptions, without some explanation being offered, phenomena cannot be understood (Parpio, Malik, Punjani & Farooq, 2013). For critical realists, the best explanations are those which have the greatest explanatory power, as research from this perspective definitively aims to extend and deepen understandings beyond identification of phenomena; exploring the intricacies that encircle lived experience, and the knowledge gained accordingly (McEvoy & Richards, 2006). Hence, the methods of exploration employed by critical realists tend to be essentially
adaptive; usually dictated by the line of inquiry and research questions under investigation, rather than methodologically bound (Parpio et al., 2013).

Initiated by Bhaskar (1989, as cited in Gorski, 2013) and later developed by scholars such as Collier (1994), critical realism assumes that reality is stratified or multi-layered, comprising biological, psychological, social and cultural levels, and asserting that complex social phenomena cannot be explained by, or reduced to, the “generative mechanisms” operating at any one level alone (Wikgren, 2005, p.14). Hence, when applied to health and illness, critical realism endeavours to unify the biomedical and the psychosocial (Ussher, 1999a), and illuminate the interactions between these related entities (the importance of this for the current inquiry was prior discussed in Chapter 2, see 2.3). It acknowledges the mutually influential relationship between the person and the social whereby humans shape the very society which serves to inform human activity. According to Bhaskar (1989), to understand and change the social world it is essential to identify the subsurface mechanisms that give rise to specific phenomena, and to consider their role and influence regarding human agency. This is particularly important where critical realism is applied to social science, as it enables researchers to distinguish between events which occur (i.e. the ‘actual’), the structures underlying those events (i.e. the ‘real’), and what is observable (i.e. the 'empirical’) (Archer, 1998, Morton, 2006). Critical realism accepts that knowledge is not value-free and importantly articulates bias, typified by the role of the researcher in knowledge production and presentation; recognition of which is considered honest and enriching for analysis (Gough, 2003). It also agrees with the hermeneutic view that knowledge is “communicatively constructed”; positioning knowledge as conditional and, as such open to scepticism, challenge and critique (Wikgren, p.14).
As critical health psychologists question the underlying assumptions and implications of mainstream health psychology and traditional research methods (Murray, 2015), critical realism is sceptical of alternative philosophical perspectives; particularly those which accept reality ‘as is’ only on the basis of what is observable (positivism), and positions which are dismissive of ontological matter (postmodernism) (McEvoy & Richards, 2006). Conversely, critical realism prioritises ontology, and though it values epistemology, ontological existence in this domain “does not necessitate epistemological awareness” (Levers, 2013, p.2). It rejects the notion that ontology is merely reducible to epistemology and that “what we think is all what is” (Bhaskar, 1997 as cited in Wikgren, 2005, p.14). Bhaskar critiques this idea, describing it as “epistemic fallacy”; in essence, muddling issues of ontology and epistemology by inappropriately providing epistemological answers for ontological questions, and reifying existence only on the grounds of knowledge. Opposing this, critical realism importantly distinguishes between the two. It embraces an ontological sensibility which refuses to deny independent realities and appreciates unobservable influences, while simultaneously accepting that knowledge is “historically transient”; subsisting according to time, space and context (Nunez, 2013, p.202).

Further, critical realism also opposes radical constructionist positions that suppose reality is socially constructed, claiming instead that social representations of reality are what are constructed rather than reality itself (Pilgrim & Bentall, 1999). Like social constructionism, it recognises the mediating role of contextual mechanisms on representations of reality and defends the possibility of causal explanations by identifying “causal powers”, i.e. principles which influence the occurrence of phenomena (Wikgren, 2005, p.12; Elder-Vass, 2012). Equally, it considers the study of phenomena in context to be indispensable for improved understandings and useful knowledge production (Pilgram & Bentall, 1999). However, unlike social constructionism, critical realism does not essentialise the study of discursive practices.
above all other sociocultural “forces” and “interests” (Pilgram & Bentall, 1999, p.262); rather, it considers that all social determinants are systemically important and views these through a holistic lens, allowing for exploration of the micro- and macro-systems serving to shape theoretical assumptions, investigative methods and experiential accounts (Walsh & Evans, 2014). Hence, the applicability of critical realism to the current inquiry, which aims to achieve a holistic understanding of men’s breast cancer experiences and produce broader knowledge with respect to men’s related constructions and meaning-making; going beyond essentialist thinking (see Chapter 2, section 2.1.1).

Looking more specifically at the context of health/illness, understanding the wider forces that govern social determinants of health (e.g. power relations, economic policies, political systems, etc) is said to be key to addressing health inequalities (WHO, 2016). Critical realism provides an ontological platform for health researchers to make sense of health and illness and the structures underlying health agency. Parpio and colleagues (2013, p.493) argue that critical realism is philosophically strong and “potentially functional” as an approach to health research, since it offers a flexible framework to guide appropriate health action, and constant evaluation in developing health practices and interventions. Further, as Wainwright (1997) notes, it presents as a viable option for studying health and illness phenomena because it affords researchers the opportunity to explore observations within both known theoretical and social structures, and to adapt investigative methods for research as they see fit. For McEvoy and Richards (2006), critical realism’s pliant nature is its philosophical fortitude, as adaptability facilitates deeper levels of exploration; therefore, deeper understandings of the real, the actual and the empirical can be established (Elder-Vass 2015). The usefulness and applicability of critical realism in the context of health and illness is further championed by Clark, Lissel and Davis (2008). According to Clark et al., critical realism is particularly efficacious for understanding complexities, refining interventions and exploring
biopsychosocial pathways. Further, critical realism can also be regarded as ‘patient-centred’, given its links with social action and emancipatory goals to unshackle and empower marginalised patient groups and individuals; and, the appreciation it demonstrates for shared values as well as individuality and local truths (Parpio et al., 2013). The adoption then of a critical realist ontology here is both appropriate and justified; the researcher accepting the marginalisation of men with breast cancer as a social ‘reality’, while exploring the generative structures behind marginalising acts and discourses relatedly and working to further understandings regarding social constructions of both breast cancer and masculinity.

Where ontology asks ‘what is there to know?’ epistemology asks ‘how can we know something?’, questioning the nature and scope of emerging knowledge, as well as the validity and reliability of knowledge claims (Willig, 2013). The research draws on two epistemic bases: phenomenology and participatory research (PR), or rather it is informed by adapted formats of these two philosophies, merged together for the same inquiry. Establishing the philosophical positioning of the research was essential in order to make meaningful sense of the men’s breast cancer accounts and to comprehend the relationship between the knowledge gained and the ‘knower’ (researcher) (Denzin & Lincoln, 2005). Inherently distinct and informed by different research paradigms phenomenology and PR arguably present as challenging for combination with competing ontologies and epistemologies. However, despite clear differences, synergy of the two approaches and the qualitative methods they employ is possible and potentially advantageous for critical health inquiries, as is explained following an introduction to each perspective.

4.1.2 Phenomenology

Phenomenology is an inductive research approach which investigates subjective human experience (Willig, 2013), and thus lends itself to the current inquiry which focuses on men’s
breast cancer experiences. Like critical realism, phenomenology can also be described as an in-between philosophical position, as although phenomenologists maintain that experience is constructed rather than determined, they concede that it remains real to the experiencer (Willig, 2013). The term phenomenology is widely adopted in qualitative research, and a variety of techniques are practiced under the guise of phenomenological inquiry (Mayoh & Onwuegbuzie, 2015; Finlay, 2009). This has led to disagreement regarding both definition and conceptualisations of phenomenology, and also some debate as to whether it is best understood as a research method or philosophical context (Langridge & Ahern, 2003). Here, it serves as both; providing in part a foundation from which to develop the research investigation, while also informing methods of both data collection and analysis. On the one hand, the research follows phenomenological tradition; collecting data through qualitative in-depth interviews, to produce first-hand accounts of men’s individual descriptions of the lived breast cancer experience (Lopez & Willis, 2004). On the other hand, the application of phenomenological inquiry to visual data forms is less well-established (Benner, 1994); though the approach continues to make strides in the social sciences and qualitative research (Spencer, Nilsson, Wright, Pirl & Prigerson, 2010; Banks, 2008). As Garza (2007, p.338) notes, “the flexibility of phenomenological research and the adaptability of its methods to ever widening arcs of inquiry is one of its greatest strengths”.

Phenomenology as a discipline offers multiple schools of thought, and findings generated through phenomenological research depend on the researcher's philosophical standpoint (Lopez & Willis, 2004). Two major approaches dominate phenomenological inquiries: descriptive phenomenology, i.e. pure phenomenology as it was first introduced by founder Husserl (cited in Woodruff Smith, 2013); and, interpretive phenomenology, a revised version informed by hermeneutics, proposed by Husserl’s successor, Heidegger (cited in Reiners, 2012). Several variations of phenomenology have since developed from these separate yet
related philosophical bases (see Gadamer 1975; Giorgi, 1985; van Manen, 1990), and contemporary forms inspired by the works of Husserl and Heidegger continue to evolve (Dowling, 2007). Hence, phenomenology is often referred to as a philosophical movement; considered non-static, with ideas consistently being reviewed (Lopez & Willis, 2004); much like CHP, where emphases are constantly changing and developing (Hepworth, 2006).

Principally, descriptive and interpretive phenomenological inquiries differ both in how they generate research findings and utilise them to inform knowledge. Husserlian (descriptive) phenomenology is strongly epistemological, positioning experience as the fundamental source of knowledge (Dowling, 2007). Husserl supposed that it is possible, essential even, to establish one correct and generalisable interpretation, that is objectively free from preconceived ideas or prejudices held by the researcher about the research phenomenon prior to investigation (Dowling, 2007). Further, his thinking also discounted the potential influence of aspects that go beyond the consciousness of the experiencer, e.g. culture, power, politics etc. Husserlian conceptions are therefore incongruent with the premises of CHP – the overarching framework for the current inquiry (see Figure 2); a paradigm which reflects a move away from the rigidity of traditional science and realises that multiple understandings are possible and explicitly takes into consideration the wider social environment within which human experiences occur. With this in mind, and also the intentions of the current research, i.e. to gain a holistic understanding of how men experience construct and make sense of breast cancer, and their masculinities accordingly, interpretive hermeneutic phenomenology is therefore better suited to this line of inquiry; the reasons for which will now be discussed.

As Todres and Wheeler (2001, p.3) explain: “the lifeworld is always more complex than anything we can say about it: the lived experience is greater than the known”. Acknowledging this, and in contrast to Husserlian phenomenology, contemporary
phenomenology rejects natural science and instead favours a qualitative human science approach; concerned with how individuals make sense of “being” and how this information is expressed (Todres & Wheeler, 2001). The transition into an existential hermeneutic phenomenology is thought to be especially productive for qualitative health research, offering a “fertile direction” for exploring health-related experiences and associated meaning (Todres & Wheeler, 2001, p.2). Counter to Husserlian conceptions, Heidegger prioritises interpretation over description; less concerned with what humans consciously know, and more so with what they imply about their experiences (Soloman, 1987). In accordance with hermeneutics, interpretive phenomenology seeks to elicit aspects of human experience and relations that are typically hidden; perhaps even consciously from the experiencers themselves (Lopez & Willis, 2004). It goes beyond mere descriptions to generate a deeper level of understanding and achieves this through analysis of the lived experience inside its meaningful context. For Heidegger, meaning lies in interpretation, and humans experience phenomena as something which has already been interpreted, so interpretation is not viewed as a secondary procedure, but rather as an ongoing process; and any knowledge produced as subject to alternative interpretations (Finlay, 2009).

Where Husserl’s goals are epistemological, centred on providing a foundation for knowledge, Heidegger’s focus is more ontological, characterising human existence as Dasein, i.e. “being there”; explicitly concerned with how human beings operate within and relate to their lifeworld (Larkin, Watts & Clifton, 2006, p.106). Thus, interpretive phenomenology does not position human experience or experiential descriptions as devoid of the wider social context; rather, it asserts that the person and the social are so intertwined that subjective experiences are inextricably linked with the socio-cultural-political contexts in which they emerge, and which provide the linguistic tools to articulate them (Dreyfus, 1991). Further, it opposes the idea of “radical autonomy” ‘through the counterargument that freedom is situated, not
absolute as Husserl implies (Smith, Flowers & Larkin, 2009, p.176). Interpretivists argue that humans are indelibly “persons-in-context” and that choice is contextually circumscribed, therefore it can never be wholly “free” (Larkin, Watts, Clifton, 2006, p.106). “Situated freedom” is said to be the existential reality from which all meaning arises and choices are established (Lopez & Willis, 2004, p.729). In view of this declaration, understanding how meanings are described and influence human choice is central to interpretive phenomenological inquiry.

One critical difference between descriptive and interpretive approaches is how the researcher’s knowledge of the study phenomenon prior to investigation is valued and managed. In contrast to the descriptive tradition of phenomenological reduction, which advocates that researchers rid themselves of all former knowledge and neutralise their personal biases to know the phenomenon only as it is described, the interpretive approach realises the impossibility of this, and further postulates that such practices may even be detrimental to the research process (van Manen, 1990). Without forming some preliminary assumptions about the meanings behind a phenomenon, understanding cannot be established (Willig, 2013). Further, there is a circularity supposed between preunderstanding and understanding through which the researcher is said to move back and forth when interpreting meaning. Hermeneutic phenomenologists refer to this concept as the “hermeneutic circle”; proposed to illustrate the reciprocity of understanding, i.e. that the whole can only be understood through understanding its parts, and vice versa (Landridge, 2007, p.122). According to Koch (1995), a researcher’s presuppositions about a given topic are primarily what cause them to investigate it, and/or to realise a research gap. The researcher’s knowledge base then serves as a valuable and necessary guide for developing lines of inquiry that are both practicable and meaningful, and for producing useful knowledge (Lopez & Willis, 2004). Interpretive phenomenology therefore works with and uses these
presuppositions rather than negates their influence, arguing that this leads to advanced understandings about meaning-making (Willig, 2013).

Further, the interpretive approach emphasises the co-constitutionality of phenomenological research. This is the conception that meanings about human experience established through interpretive inquiry are co-created between the researcher and the study participants – positioned as “co-researchers” – resulting in an intersubjective interpretation of the research phenomenon (Merleau-Ponty, 1964/1968, p.138 as cited in Finlay & Evans, 2009); again, demonstrating linkage with CHP, which also situates participants as joint contributors in the research process. For researchers adopting a critical stance, it is important to realise this co-construction and to adequately reflect on the researcher–co-researcher relationship when discussing insight and voice gained from the research; and also, to accept that both remain constrained despite such realisations (Finlay, 2009). While interpretive phenomenology advocates reflexivity, the extent to which researchers should attend to their own subjectivity is widely debated. Scholars caution against researchers becoming preoccupied with personal reflexivity, warning that this may prevent them from being open to the ‘other’ and fresh perspectives, and unhelpfully shift attentions away from the research participants and study phenomenon (Finlay, 2009). Nevertheless, those of hermeneutic sensibility – particularly critical hermeneutics – agree that researchers need to be critically self-aware of their own subjectivity and its role within the research process (Finlay, 2008), as mentioned previously (4.1, see also 9.9).

Furthermore, critical hermeneutics advises that researchers should engage more critically with experiential accounts by adopting hermeneutics of suspicion over one of faith (see Josselson, 2004); that is to treat given accounts as the product of social and psychological processes calling for explanation and interrogation, rather than naively accept them as
authentic representations (Flick, 2013). Critical hermeneutics assumes that interpretations are habitually influenced by socially accepted ways of viewing reality, reflecting the values of privileged persons accordingly, while the voices of marginalised individuals go unheard (Lopez & Willis, 2004). For researchers exploring lived experiences of marginalised groups, this thinking may be particularly fruitful; given its emancipatory potential to uncover less popularised ways of seeing social realities, and also that it encourages researchers to probe given accounts further to ascertain embedded influences, e.g. power (Lopez & Willis, 2004).

However, in line with Smith’s considerations (Smith, 2004 as cited in Flick, 2013), the current research demonstrates an appreciation for hermeneutics of both suspicion and faith; casting a critical, reflective eye, whilst simultaneously treating the men’s breast cancer accounts with an empathic attitude (Flick, 2013); positioning men as co-researchers as opposed to simply participants, and experiential experts, given their embodied knowledge of the illness. Hence the application of IPA as the analytic approach; the suitability of which is discussed later in this chapter (4.4).

As this particular inquiry embraces elements from across the variations of phenomenological methodology, and indeed other philosophical perspectives, it is perhaps best viewed as a phenomenologically inspired exploration of men’s breast cancer experiences as opposed to exactlying phenomenological (Wertz, 2005). Though the research predominantly leans toward the conceptions of interpretive hermeneutic phenomenology, it still seeks to present rich descriptions of the men’s lived breast cancer experience in their appearing – a Husserlian intention – but crucially realises that given accounts are situated, and importantly considers the influential role of both participant and researcher subjectivities. To ensure the quality of the study findings, the current research looks to generate a “phenomenological nod” (van Manen, 1990, p.27) from the men interviewed, i.e. affirmation that the critically reflective second-order interpretations offered represent their breast cancer experience insofar as their
own understandings of it. Yet it also seeks to go beyond this, and through careful interpretation reveal embedded facets which may be less apparent to the men themselves, furthering understandings through critical interpretation of subsurface material.

4.1.3 Participatory Research (PR)

As mentioned above, along with phenomenology, the research is also informed by participatory research (PR; see Cargo & Mercer, 2008, and Bergold & Thomas, 2012). PR serves as “an umbrella term for a school of approaches that share a core philosophy of inclusivity and of recognising the value of engaging in the research process those who are intended to be the beneficiaries, users and stakeholders of the research” (Cargo & Mercer, 2008, p.326). Hence, like phenomenology, PR has been defined in multiple ways by many researchers from various fields of inquiry (MacDonald, 2012). Nevertheless, PR is generally considered an equitable effort between the researcher and the researched, broadly explained as “systematic inquiry with collaboration of those affected by the issue being studied, for the purposes of education, taking action or effecting change” (Green et al., 1995 as cited in Cargo & Mercer, 2008, p. 327). PR therefore presents as a counter hegemonic approach to knowledge development, challenging mainstream epistemologies and traditional qualitative techniques by offering radical alternatives, designed to liberate research and empower study participants (Bergold & Thomas, 2012); therefore, it fits well with CHP as the overarching paradigm framing this research. Differentiating itself from dominant positivist positions and conventional research, PR posits that understanding social phenomena is not enough, and that research should strive to be progressive; leading to greater insight and/or change (Minkler, 2000).

Philosophically, PR is predominantly underpinned by feminism, critical theory and constructivism (Kindon et al., 2007; Baum, MacDougall & Smith, 2007) and as such is
congruent with postmodern tradition; embracing the changeable nature of understanding, recognising that multiple realities exist and accepting that objectivity is unattainable (Kelly, 2005 as cited in MacDonald, 2012). How the different schools of thought engage with PR and make use of the diverse methods employed for PR varies depending on their level of commitment to the approach (Kindon et al., 2007). Methodologically then, PR is difficult to typify (Brydon-Miller, 1997) and is perhaps best viewed as a “research orientation rather than a specific method” (Minkler, 2000, p.191).

Feminist contributions to PR are particularly noteworthy, insightfully informing the epistemology, theory and practice of the approach. Further, feminist insights are especially pertinent to the research in question; encouraging researchers to acknowledge gendered divisions between participants (Kindon et al., 2007). This is especially worth considering here given that the research critiques the gendering of breast cancer and explores factors contributing to gendered understandings of the illness. Consistent with feminist tradition, the principle goals of PR are to: empower oppressed individuals, challenge traditional research hierarchies, and engender equity and change for improved human existence (Fals-Borda, 2001). Seeking to circumvent unjust power differentials, PR presents as an enlightened approach to the study of human inequalities; however, like other approaches, it too is enmeshed with power and has the propensity to produce both positive and negative power effects. For instance, while it serves to liberate and enable participants, it presumes that participants want to be emancipated; something which researchers must critically consider when identifying potential issues for change (Kindon et al., 2007). For example, in the context of the current study, there is the assumption (e.g. Halls, 2013) that men with breast cancer want to be de-marginalised, and that giving voice will benefit the men rather than detriment them further; although the study sample may disagree.
Ontologically, PR sees reality as socially constructed; as fluid, not a fixed or singular entity awaiting detection (Kindon et al., 2007). Rather for PR, realities are out there; emergent and pluralistic, with multiple interpretations of a single phenomenon assumed possible (Greenwood & Levin, 1998), and humans positioned as agentic beings capable of reflexivity (Kindon et al., 2007). Likewise, epistemologically, PR also considers a plurality of knowledges to exist across a variety of institutions, unlike traditional epistemologies which assume knowledge is confined to academy and policy (Kindon et al., 2007). PR characterises an epistemology which rejects the idea that human consciousness is merely a reproduction of external reality, arguing instead that what is realised is critically reflected on prior to conscious awareness, as well as post-experientially (Baum et al., 2007). This bears a resemblance to Heidegger’s belief that experience is pre-interpreted (Finlay, 2009), and like Heideggerian phenomenology, PR also considers that people are situated social beings who must be understood in context (Fals-Borda, 2001). In contrast to positivists like Husserl, who viewed the scientific world as an abstraction from experiential reality, PR values context and seeks to understand lived experience from within rather than outside of its cultural, societal and political foundations (Baum et al., 2007). Reason (2006, p.189) considers this an “extended epistemology”, i.e. the capacity to adopt a comprehensive worldview which draws on diverse understandings to inform human action rather than one dominant perspective (Kindon et al., 2007).

PR’s commitment to substantiating local context while simultaneously aborting the quest for scientific ‘truths’ has prompted frequent criticism, namely that the approach is methodologically ‘soft’ for valuing voice and intangible aspects of human experience over observable material (Young, 2006). However, once a method at the margins of valued scientific research, PR is said to have “come in from the cold” and is fast becoming a leading approach in the human sciences, suited to a range of disciplines; though it remains firmly
situated within critical research arenas (Kindon et al., 2007, p.1). As acceptance of PR as a legitimate research methodology increases so too does the application of PR to health and illness research (Cargo & Mercer, 2008). PR is now a popular approach in critical health psychology, and the progressive turn towards creative and innovative research methods in psychology over time has seen a particular embracement of participatory visual methods in studies exploring marginalised and underprivileged patient groups (Murray, 2015; Topcu, 2015). Where these people and their health circumstances may be otherwise overlooked, PR – like CHP – acknowledges their emic knowledge as insiders or “experiential experts” (see Murray, p.118) at the heart of the research inquiry; providing an efficacious approach for including marginalised beings and their non-dominant views which are typically assumed less important yet are crucial for understanding and improving health (Rohleder, 2012; Estacio & Marks, 2007). PR supposes that those most systematically denied reveal the greatest insight regarding the mechanisms behind unjust social arrangements (Kindon et al., 2007). However, consistent exclusion can prompt a reluctance to engage with research and/or people in dominant positions, e.g. researchers, healthcare providers etc., meaning that the views of these individuals may be hard to reach.

Visual forms of PR can be particularly useful when recruiting those less au-fait with or simply less inclined to participate in qualitative research, e.g. marginalised men (Sopcak, Mayan & Skrypnek, 2015), and when studying topics of a sensitive nature that people may find difficult to discuss, e.g. a life-threatening diagnosis; providing participants with more than one means by which to express themselves in giving voice, which in turn is thought to foster richer experiential accounts (Rose, 2012, Tinkler, 2013). Methods such as participant-generated photography – whereby participants capture their experiences on camera – are increasingly being used in health psychology, and the critical variant of the discipline; enabling researchers to gain a fresh perspective on people’s health/illness experiences
(Topcu, 2015). Capable of gathering experiential detail that traditional data collection methods are less likely to achieve, visual methods also help to generate knowledge more closely centred on individuals’ real experiences of health and illness, and can thus facilitate better understanding among health professionals, researchers and policymakers alike (Topcu). A further strength of visual participatory methods is that they can be used in conjunction with other qualitative methodologies, making them suitable for multi-methodological approaches, which are gaining considerable popularity in contemporary research (see Chamberlain, 2012). According to MacDonald (2012), the combination of PR with other qualitative techniques presents as a potentially successful means for addressing health inequities and for fostering patient empowerment; hence the decision to draw on PR theoretically and to adopt a participatory methodology for the current inquiry.

4.2 Integrating perspectives: challenges and opportunities in multi-method inquiry

Having outlined the paradigmatic underpinnings of the research methodology, it is clear that while the perspectives are distinct and adhere to competing ontologies and epistemologies, there is also a degree of overlap between the research orientations, indicating their suitability for integration with one another. Despite some notable tensions between the perspectives, essentially, they each embrace an inductive interpretive and holistic approach to understanding lived experience, with the purpose of giving voice to and empowering relevant individuals; each relinquishing some degree of control to study participants, recognising the value of positioning participants as co-researchers, and also the need for dual reflexivity. They each agree that experiential accounts are context-dependent and constructed according to power and sociocultural influences and accept that multiple interpretations of a single phenomenon and of any knowledge produced accordingly, are possible. Finally, each
approach is adaptive and demonstrates emancipatory potential, indicating their applicability to the study of health and illness and marginalised populations. A combined methodological approach which embraces elements of critical realism, phenomenology and PR in accordance with critical health psychology seemingly then offers a suitable, flexible framework for exploring men’s breast cancer experiences.

Integrating methodological perspectives as proposed here does though present challenges. Although combining multiple qualitative methodologies arguably does not encounter the same level of epistemological challenge as qualitative-quantitative combinations, critics argue that qualitative consistency does not quell epistemological debates, or assure methodological compatibility (Barnes et al., 2014; Gil-Garcia & Pardo, 2006). Scholars in favour of methodological purism question whether multi-method approaches are in fact more insightful, nuanced and data-grounded than mono-method research as pluralists’ claim, as richness and sophistication of findings can never be guaranteed, and remain largely dependent on the researcher’s analytical capabilities irrespective of the methodological approach (Barnes et al., 2014). Further question marks also hang over multi-method research on a practicality front too; combining methodologies typically demands greater amounts of time and resources, plus, it can be harder to ‘sell’ less well-defined methods to funding agencies and journal editorial boards, which typically favour established methodologies (Gil-Garcia & Pardo, 2006). Nevertheless, advocates (e.g. Shaw & Frost, 2015) of multi-methodology argue that the value of combining different epistemologies and methods together in a single piece of research outweighs such challenges and is preferable to a mono-methodology for a variety of reasons (see also Papaloukas, Quincey & Williamson, 2017).

A counterargument to methodological purism is that no single methodology or method is inherently superior to any other; rather all research approaches have their place and their
relative advantages and disadvantages depending on the research scenario (Barker & Pistrang 2005). “Knowledge accumulates from a variety of sources in a variety of ways” (Barker & Pistrang, 2005, p.202), thus combining methodologies is frequently endorsed on epistemological and ontological grounds (Barnes et al., 2014), given the potential to gain knowledge about different aspects of the study phenomenon (Mingers, 2001) and to uncover paradoxical findings which may foster further research (Gil-Garcia & Pardo, 2006). As Frost and Nolas (2011, as cited in Barnes et al., 2014, p.3) noted, “contemporary experiences are multi-dimensional and worlds are multi-ontological”. In drawing on multiple perspectives, researchers can focus on different aspects of reality and possible ways of being, enabling them to extract more meaning from participants’ accounts, and to produce complex and multi-layered explanations about their experiences (Mingers, 2001; Barnes et al., 2014). Multi-methodology also permits triangulation of findings, helping to deepen interpretations, further understandings, and prevents methodological bias (Gil-Garcia & Pardo, 2006; Mingers, 2001). Further, in comparison to single-method designs, multi-method approaches have “considerable potential to realise deeper forms of reflexivity”, offering greater transparency of the research process and researcher proclivities (Barnes et al., 2014, p.8); this, a particular strength of multi-methodology, especially when used in critical inquiries which explicitly aim to improve research transparency (Murray, 2015).

Although qualitative researchers are frequently criticised for failing to adequately understand the theoretical lens that serves to guide their research, equally, some scholars warn of the potential consequences of becoming too concerned with methodological minutiae. Chamberlain (2000; 2012) highlights the issue of methodolatry in qualitative health research; that is preoccupations with methodological purism and an overvaluing of methodology, prompting a privileging of methods over other apposite considerations, which potentially leads to an inflexible research approach and restricts researcher engagement accordingly.
While it is accepted that researchers should engage appropriately with the underlying epistemological assumptions and theoretical thinking behind their chosen approach, Chamberlain (2012, p.6) argues that “the use of methodology should never be methodolatry”. Like Chamberlain, Lee (2006) and Willig (2013) also caution researchers against overly immersing themselves in the subtleties of methods or epistemologies, advising instead that researchers focus on identifying and clarifying precisely what type of knowledge their research aims to produce, and thoughtfully select appropriate methods to generate that knowledge. Methodological conceptualisations may inform the research, but methods should be developed and adapted in context in order to generate relevant data that can be suitably analysed to provide insight into the study phenomenon being investigated. Methods should thus be viewed as means rather than ends, or as Kvale (1996a) explains it, the way to the goal. They should be selected so as to produce data that are appropriate to the specific research question(s) being answered, and scholars now recognise that this may require the use of multiple methods simultaneously (Chamberlain, 2012).

Adoption of prescriptive ‘off-the-shelf’ methodologies is arguably then inappropriate in the context of the current inquiry, not least because the fundaments of critical qualitative research oppose rigid codifications and narrowed practices (Cannella, Perez & Pasque, 2015), but also because they inappropriately confine critical health research and thus limit research potential. To quote Sigmund Koch, who criticised psychologists for valuing science and method above human nature, psychology research should explore “humanly significant problems with methods chosen or devised with intelligent flexibility to fit with the problem being pursued” (see Smith, 2001, p.443). In agreement with this statement and recognising the potential benefits of multi-methodology for critical health psychology inquiries, the current research embraces a multi-method approach to data collection that employs two qualitative techniques, producing two forms of qualitative data (verbal and visual); both sufficiently flexible to
operate together to achieve the research aims and objectives, and to generate experiential knowledge about men and breast cancer. Combining methodologies in this way not only offers a more comprehensive approach to the study topic, it may also serve to reduce the limitations of either method by off-setting them against the other’s strengths (Barnes et al., 2014), adding rigor to the research process and study findings. Nevertheless, the researcher is mindful of the tensions that exist between the combined methodologies, particularly between the individualism and critical realism of IPA, and the collectivist and more realist position of PR; and the need to carefully manage these tensions, if this combination is to be successful. This is discussed further in Chapter 9 (see 9.5).

4.3 Methods of data collection

Selected in accordance with the line of inquiry, the theoretical thinking behind the research and on the grounds of methodological compatibility with one-another, semi-structured interviewing was the choice technique for collecting verbal data, while 'visual voice' – an adaptation of Photovoice methodology – was used to gather the men's visual representations. In combining these two methods the researcher anticipated providing an alternative and interesting approach to understanding the experience of breast cancer in men, and a more complete explanation of illness in men. The fittingness of each method is discussed below in turn.

4.3.1 Semi-structured interviewing

In contrast to structured interviewing which typically comprises a rigorous set of questions from which the researcher does not usually divert; semi-structured interviewing uses an open form of questioning that fosters new ways of experiential thinking. Designed to stimulate rather than dictate discussions, the aim is for researchers to co-create meanings with participants, and work collaboratively to reconstruct understandings of specific human
experiences (DiCicco-Bloom & Crabtree, 2006; Tracy, 2012); this very much in keeping with the premises of CHP (Murray, 2015). Guided by an interview schedule (pre-devised by the researcher, informed by previous literature, empirical findings, and in the current context, discussions with a research partner who advised on content and phrasing), used predominantly to maintain sight of the primary research questions and to provide participants with some guidance on what to talk about, semi-structured interviewing affords researchers the flexibility to probe novel avenues of interest as they arise; allowing for the discovery of information that is important to participants, but that the researcher may not have thought pertinent before the interview (Gill, Stewart, Treasure & Chadwick, 2008). The schedule also serves as an aide-memoire for researchers, calling to mind matters previously explored that they wish to discuss in greater depth, as well as issues that they consider have previously been overlooked (either intentionally or merely missed), and fresh considerations yet to be broached. Semi-structured interview schedules are adaptable and can be used more or less depending on the flow of talk and the participant’s level of engagement. Questions can be re-ordered and re-phrased throughout the interview to suit the linguistic repertoires and sociocultural understandings of the participants, and/or adjusted in accordance with their responses and interview pace; facilitating more fluid discussions and greater rapport between the researcher and participants, tailoring interviews to accommodate and respect their individual differences (Barriball & While, 1994; DiCicco-Bloom & Crabtree).

Spradley (1979) claims that successful interview schedules comprise a combination of four types of questions: descriptive (biographical inquiry), structural (knowledge organisation), contrasted (draw comparisons) and evaluative (feelings, affect). Usually, schedules start general then gradually become more specific and probing as rapport builds (Willig, 2013); enabling the researcher to delve deeply into the social and personal meanings people attach to experiences (DiCicco-Bloom & Crabtree, 2006). In semi-structured interviewing the
researcher assumes the position of both listener and reflector as much as – if not more than – questioner (Tracy, 2012), and is actively encouraged to recognise the role they and their prior assumptions have in shaping questions and responses (Willig, 2013). The quality of the data achieved largely depends on the researcher’s ability to understand their role and employ the necessary practical and interpersonal skills required of them at the data collection stage (Patton, 1990). For example, though the researcher has license to adapt and re-phrase questions as they see fit, an equivalence of meaning must be conveyed in doing so to facilitate comparability of accounts (Barriball & While, 1994). Also, there is an expectation that researchers are suitably prepared to pick up on and deal with emotional cues articulated by participants; that interviews will be conducted ethically with appropriate sensitivity, ensuring that participants leave the interview as they enter it (Willig, 2013). Though the method may be considered participant-led in the way that it cedes control of the discussion to participants (Tracy, 2012), ultimately, semi-structured interviews are still driven by the researcher’s line of inquiry and research motivations (Willig, 2013). This is especially worth noting where the method is employed for studies inspired by critical and participatory perspectives which strive for balanced participant-researcher power relations.

Nevertheless, semi-structured interviewing unequivocally affords participants greater control and power over how and what is discussed than structured formats (Low, 2012). Further, the non-directive nature of the semi-structured approach typically creates a more relaxed research environment, reducing a number of the formalities usually associated with structured interviewing, e.g. ordered discussion. As a result, account giving is less constrained, prompting participants to reveal much more about the meanings they assign to their experiences; meaning that researchers are more likely to tap both content and emotional levels, potentially leading to richer data and interpretations (Tracy, 2012; Sparkes & Smith, 2013). Allowing participants space and time to give voice on their own terms as semi-
structured interviewing does provide researchers with deeper insight than other less adaptable data collection methods might offer (Sparkes & Smith, 2013). However, as Willig (2013) notes, researchers must take care not to abuse the informality of the semi-structured approach and should refrain from coercing participants to disclose more information than is comfortable for them. Supplementary information can however be gleaned from contextual and non-verbal information and can be equally as fruitful as verbal content. Consideration of and the value attached to the implicit subtleties shown in account giving is a particular strength of semi-structured interviewing, enabling more holistic interpretations of the experiences and phenomena under investigation (Pietkiewicz & Smith, 2014).

The flexible nature of semi-structured interviews means that the method can be performed in a variety of ways; this particularly advantageous when applied in health/illness research contexts which typically demand greater flexibility. Although usually conducted face-to-face in-person, it is possible to carry out semi-structured interviews both over the telephone and via online resources; though some scholars caution against using technological means, due to concerns that rapport may be compromised and unspoken cues missed, due to space and/or the impersonality of technology-mediated discussion (Sparkes & Smith, 2013). The possibility of technological failings can also be a cause for concern, as can ensuring participants user-abilities in technology-based interviews; nevertheless, the degree of anonymity the distance affords participants can elicit a candidness that some might be reluctant to share when interviewed in-person (Sparkes & Smith, 2013), allowing for more emic, emergent understandings to develop (Tracy, 2012). Further, the convenience of conducting interviews via technology may also be preferable for both participants and researchers – especially in chronic illness research contexts – enabling interview discussions to take place in a known, comfortable and safe environment at a time suitable for both parties,
rather than in-person where the research setting may be more formal and participation times restricted.

The adaptableness of semi-structured interviewing then presents multiple opportunities for data collection in health and illness contexts, including the potential for improved inclusivity of study participants and greater sample diversity; able to reach out to more members of the target population and importantly those in non-dominant positions, e.g. disabled, infirm individuals. Though often the sole means of data collection in qualitative inquiries, the flexibility of semi-structured interviewing makes the method a popular choice for mixed- and multi-method investigations, conveniently demonstrating alignment with a variety of methods and methodologies. As a tried and tested data collection method, it also offers assurance when paired with less customary qualitative methods, e.g. visual participatory forms. Further, as interviewing lends itself to different types of analysis; semi-structured interviews demonstrate compatibility with several analytical approaches, including interpretative phenomenology and participatory models (Willig, 2013; Newton, 2010). For Smith (2008), semi-structured interviews are the best form of data collection for interpretative phenomenological studies, well suited to in-depth personal discussions allowing researchers and participants to engage with one another in real-time (Pietkiewicz & Smith, 2014); facilitating in-the-moment interpretations that researchers can clarify with participants at interview and explore further with additional questioning as required, deepening analyses and understandings (Barriball & While, 1994; Reid, Flowers & Larkin, 2005).

Semi-structured interviewing therefore presents as a suitable method of data collection for the current inquiry for a variety of reasons; as such, the decision to adopt the approach was multifaceted. Not only are semi-structured interviews the most widely used data collection method in qualitative psychological research (Willig, 2013), the approach is explicitly
favoured by health and illness researchers (DiCicco-Bloom & Crabtree, 2006); many of whom argue that semi-structured interviews are the best method for gaining access to health and illness experiences, particularly where people already feel disempowered by their health status (Low, 2012). The adaptability of the method enables researchers to work collaboratively with participants to suit their needs and capabilities, widening participation in research by facilitating improved access through conducting interviews via various means, according to participants’ preferences. This is especially important in studies exploring already marginalised populations where people are either intentionally or inadvertently restricted from research endeavours. Further, well-suited to complex and sensitive issues where related talk typically requires some prompting, and useful for exploring topics about which little is known (Low, 2012), the method demonstrates clear applicability to the study of men and breast cancer.

As discussed above, the method demonstrates a degree of alignment with critical, phenomenological and participatory approaches respectively, but can also be applied to multi-method investigations combining research paradigms and techniques, further indicating its fit with the current inquiry which adopts a multi-methodology comprising these perspectives. The familiarity of semi-structured interviewing together with the lesser used visual data collection method employed balances qualitative tradition with creativity and innovation, providing a fresh approach yet to be applied to the study of breast cancer in men. Though merging methods does present challenges as previously discussed, semi-structured interviewing is an appropriate choice for the multi-method approach outlined and the critical health issue being explored.
4.3.2 Visual voice

Using photographic techniques to explore psychosocial aspects of health and well-being has become increasingly popular, especially participant-generated photography, which current literature highlights as an effective means for collecting data describing health experiences, and for capturing voices and visions often overlooked (Frith & Harcourt, 2007; Thompson & Oelker, 2013; Foster-Fisherman, Nowell, Deacon, Nievar & McCann, 2005). One particular technique currently gathering popularity in qualitative health psychology is Photovoice, introduced initially as ‘Photo Novella’ by developers Wang and Burris in the 1990’s (Wang & Burris, 1994); valued for its ability to reveal rich and informative data about lived experiences (Catalani & Minkler, 2010). Photovoice is a visual participatory method whereby individuals document their experiential circumstances through the medium of photography, described by Roger, Migliardi and Mignone (2012, p.490) as “an innovative tool used to identify, represent and enhance knowledge development and community action”. In its traditional form, cameras are placed in the hands of community members, enabling them to recognise their community’s strengths and concerns, and to highlight important issues for research (Wang & Burris, 1997). The resultant images are typically shared and discussed at the community-level to establish a collective consensus about the photographic findings, with key outcomes then communicated to appropriate persons in positions of power, e.g. policymakers; the aim being to catalyse social and political change and improve human experience accordingly (Berg, 2004; Wang & Burris, 1997). A flexible approach, Photovoice is open to interpretation in how it is performed and represented and is compatible with range of analytic methods, including IPA, with which it shares similar hermeneutic and phenomenological roots (Brunsden & Goatcher, 2007).
Providing a framework for participants to visually represent their experiences and perspectives on a particular issue, Photovoice enables individuals to express their views as they ‘see’ them; prioritising the insider perspective and recognising ‘insiders’ as experiential experts, using this insight to uncover areas unrecognised by other, more conventional investigative methods (Angelo & Egan, 2014). Relinquishing control to the participants and positioning them at the centre of the research process, Photovoice affords participants greater autonomy and engagement with the research; allowing for a more critical approach to the phenomenon being studied (Wang & Burris, 1997). Though initially offered as a sociological method, with some adaptation, Photovoice is also advocated for use within psychology (Brunsden & Goatcher, 2007), demonstrating particular applicability to studies with a critical health psychology focus (Murray, 2015) given its theoretical groundings in critical consciousness, feminist theory and empowerment (Topcu, 2015). According to Topcu (p.31), Photovoice “offers several distinctive contributions to health psychology and practice” and can be widely adapted to achieve various health psychology research objectives. Used to research various experiences of different, often disenfranchised populations, Photovoice has already been applied to a wide-range of health issues, including women from ethnic minorities with breast cancer (e.g. Poudrier & Mac-Lean, 2009; Lopez, Eng, Randall-David & Robinson, 2005); though to date, Photovoice studies with a breast cancer focus have only considered women’s experiences with the illness, neglecting men’s perspectives. Hence justifying the method’s applicability for the current inquiry.

The act of taking photographs is accessible to many people and for most is an enjoyable activity that can be conducted with relative ease; never more so than in the contemporary world where camera-enabled devices have become an essential part of daily life. Photographs are powerful messengers that can transcend all levels of social life, providing an alternative means by which to express lived experiences beyond mere words, adding another dimension
to giving ‘voice’ (Tinkler, 2013). Participant-generated photographs afford researchers the opportunity to peer into participants’ everyday lives through the eyes of the experiential beings themselves (Tinkler, 2013); the camera able to take the researcher where s/he otherwise cannot go, providing ‘ethnography by proxy’ (Bloustein & Baker, 2003, p.72). The diverse ways in which photographs can be used to creatively represent experiences and capture varied and complex information demonstrates the suitability of using photographic techniques like Photovoice to explore health and illness experiences; events which people often find too difficult or abstract to articulate (Frith & Harcourt, 2007). Photographs can therefore offer an additional mode for participants to communicate their experiences that other, more mainstream qualitative approaches, may not bring to light (Frith & Harcourt, 2007). The retrospective nature of photographic methods, i.e. talking about them days or weeks after the photographs are taken, can also trigger memory recall, serving to remind participants about forgotten aspects of their experiences that may be critical for improved understandings (Rose, 2012). Further, this retrospect affords participants the opportunity to reflect on past experiences from a present perspective, which in the context of health and illness may be particularly cathartic; helping participants to realise positive illness outcomes and their resilience and resistance to adversity (Burles & Thomas, 2012).

While the practice of taking photographs is generally considered easy for most, that people can easily convey their views and experiences through photographs should not be assumed (Drew, Duncan & Sawyer, 2010). The freedom and flexibility of creative methods is not always preferable; participants may find expressing themselves photographically more challenging than simply discussing their thoughts, feelings and emotions with researchers. Further, concerns over their artistic abilities and feeling pressured to produce ‘good’ images that meet with researchers’ expectations can hinder visual representations and account giving (Tinkler, 2013). Participants generating visual accounts must also negotiate a variety of
practical and ethical issues that may inhibit them giving voice via visual means; for instance, being device literate, obtaining permissions to take photographs and establishing rights over photographic material all serve as possible barriers. Further, it may also be difficult practically for those with limited dexterity or more profound disabilities. Consequently, people may find photographing their experiences burdensome and demanding, particularly people who are seriously unwell; hence attrition rates are typically quite high in Photovoice research (Topcu, 2015). Nevertheless, by demonstrating sensitivity to participant’s individual circumstances and flexibility in terms of what is photographed, the number of visual images taken, and how they are recorded, researchers can work with participants to overcome known issues; benefiting both participants and the research process. For example, making allowances such as permitting participants to use their own camera device rather than equipment provided by the researcher ensures user-ability and facilitates more confident photography, likely to result in improved visuals and given accounts accordingly.

A particular challenge for researchers with participant-generated photography is in ensuring that visual material is relevant to the research inquiry without influencing participants’ decisions about what to photograph and which images to include (Pauwels, 2015). It is widely assumed that generating photographs enables participants to express their personal views while exerting some control over the research process, illuminating the collaborative nature of the Photovoice approach (Tinkler, 2013). However, as with semi-structured interviewing the extent of participants control is debatable, given that photographs are ultimately influenced by participants’ perceptions of the research, the research audience(s) and the researcher-participant relationship (Tinkler, 2013); all of which are shaped in part by the researcher and their lines of inquiry. The researcher’s role is to facilitate the photo-gathering process, practically and organisationally; giving as little direction as possible with regards to what is photographed. In doing so, the eventual images are likely to be more
personally meaningful to the participants and to adequately reflect their social and cultural positioning, aiding improved contextual understandings and interpretations (Frith & Harcourt, 2007).

Researchers employing photo-based methods should not overlook the importance of the photo-gathering process. Participants’ deliberations about what to photograph and how to respond to the researcher’s brief can be as valuable as the resulting images, offering insight into participants’ initial thoughts and feelings with regards to the research and the photographic approach (Tinkler, 2013). The value of photographic data depends greatly on understanding how and why photographs are taken/selected and their meanings. It is important to recognise that participants do not always photograph what they had intended to and/or include all photographs gathered in their eventual accounts. Establishing why participants alter their photographic intentions and/or discard certain photographs may be particularly telling and is potentially as insightful as given material. Thus, probing participants about their photo-gathering practices is essential for understanding meanings attached to their photographs and experiences, and also for reflexivity purposes when evaluating the research process and knowledge generation. Traditionally, Wang and colleagues (1997) advise that Photovoice participants undergo some form of training before practicing the method; however, whether or not participants should be methodologically ‘trained’ is continually debated. While most researchers agree that some initial guidance is necessary (Catalani & Minkler, 2010), many argue that training participants to conduct Photovoice in a specific way constrains account giving and may influence how participants express themselves and represent their experiences (Topcu, 2015). Training could therefore be counterproductive to photo-based methods which seek to represent the visualisations of the participants, not the researcher.
As mentioned earlier (see 4.1.2), participatory methods like Photovoice are often critiqued for being methodologically ‘soft’ in comparison to traditional qualitative approaches. However, through detailed analysis of its content, cultural patterns and style, visual data can offer valuable insight to inform further study, especially when combined with other qualitative techniques (Pauwels, 2015). The use of photographs in research is typically a multi-method undertaking, and in qualitative research, photographs are frequently combined with verbal data forms (Tinkler, 2013). Far from a new technique, researchers have been using photographs alongside interviews since the mid-1950’s (e.g. Collier, 1957 as cited in Harper, 2002), and the inclusion of photographs in interviews has been found to yield richer, more detailed account giving than verbal-only formats (Capello, 2005). Further, verbal-only interviews are said to become unproductive sooner than interviews which incorporate visual stimuli, as the steady introduction of fresh visual material tends to hold participants interest and maintain their focus for longer than talk alone (Collier, 1957). Equally, visual data alone are also limited, and are unlikely to elucidate the full extent of meanings attached to experiences without some explaining (Pauwels, 2015). The extent to which visual images can help people to obtain ‘voice’ is debateable and is something that researchers must critically consider when employing visual methods with the intent to express voice and ‘hear’ the unheard (Pauwels, 2015). It is inappropriate for researchers to assume that visual material speaks for itself; the polysemic nature of photographs means that what participants ‘see’ is not necessarily visible to the researcher, and so without clarification, visual data may be vulnerable to many different interpretations and possibly misinterpretations (Tinkler, 2013). Scholars (e.g. Frith & Harcourt, 2007) therefore caution against researchers assuming that complex experiential meanings can be gleaned from photographs devoid of participants’ explanations, and also warn of visual material distracting researchers from what is being ‘said’. Hence, participants contributing photographic data are frequently asked to caption
and/or discuss their images to ensure meanings are appropriately understood and accurate interpretations can be drawn (Tinkler, 2013). Synthesis of the different data forms (visual-textual-verbal) is the preferred approach to data analysis, though depending on the complexity of the findings, separate analyses of the data forms may be necessary to confirm interpretations (Brunsden & Goatcher, 2007).

Compatible with multi-method inquiries, given its capacity to complement and enhance other research methods, and having previously demonstrated its applicability to the study of marginalised individuals’ experiences with breast cancer, Photovoice presents as a suitable method of data collection for the current inquiry. Though as Topcu (2015) notes, most studies using the Photovoice method present a modified version to that originally outlined by Wang and Burris (1994), and other researchers have previously used individual interviews with Photovoice in chronic illness contexts (e.g. Newman & SCI Photovoice Participants, 2010; Hermanns, Greer & Cooper, 2015). Nevertheless, for clarity, the approach here is best viewed as an adaption of Photovoice; adjusted to fit the criterion of the current inquiry. Where data are not exclusively photographic, Pauwels (2015) recommends using the term ‘visual voice’ rather than Photovoice to differentiate the method from adapted formats. Therefore, going forward, this alternative label was adopted when referring to the visual approach taken; not only to explicitly acknowledge differences between the approach and traditional Photovoice, but because visual voice also conveniently reflects the use of both visual and verbal data formats.

**4.4 Method of analysis**

Various analytical techniques exist for analysing qualitative interview data, many of which demonstrate applicability to verbal interviews but are less well-acquainted with visual methods, and arguably even lesser so with multi-methodological approaches. Where scholars
have previously highlighted the applicability of semi-structured interviewing to certain methods of analysis (e.g. IPA; Smith, 2008), no particular form of analysis is advocated for use specifically with Photovoice-style methods, or for datasets combining verbal and visual data formats (Brunsden, 2015 as cited in Banyard, Dillon, Norman & Winder, 2015). With no prescribed approach – although this is more fitting for critical qualitative inquiry as earlier mentioned – researchers are tasked with selecting an appropriate analytic framework capable of achieving the research objectives. This can be especially challenging in multi-method inquiries where competing paradigms and epistemologies underlying the methodology may restrict methodological choice. As data collection methods become more innovative and creative, analytical techniques are advancing accordingly, with variations and specialised applications of methods becoming commonplace in contemporary qualitative research. For this specific inquiry, which incorporates two flexible methods of data collection, it was important to select a method of analysis that was equally adaptable, suitable for the combined analysis of the men’s talk and photographic data, and which lend themselves to CHP and critical realism. Hence, the decision to employ interpretative phenomenological analysis (IPA, Smith 1996); a method concerned with trying to understand the personal and social realities of the participant from their perspective through empathic and critical hermeneutic questioning, and capable of adaptation, since there is no single definitive way of undertaking it (Smith & Osborn, 2007).

A fairly recent development in qualitative inquiry, IPA was first introduced by Smith in the mid-1990s, who in looking to revive a more pluralistic psychology argued for an accessible approach capable of capturing the experiential and the qualitative that could still connect to mainstream psychology (Smith, Flowers & Larkin, 2009). IPA is a psychological research method with its origins, and the majority of published IPA research, in health psychology; its primary goal to explore in depth how individuals make sense of their lived experiences.
While some (e.g. Brocki & Wearden, 2006) argue that the initial application of IPA to health psychology was merely happenstance due to its developer working within the field, IPA demonstrates particular suitability to health psychology, and indeed critical health psychology, for multiple reasons. According to Smith and Osborn (2007), IPA is “especially useful when one is concerned with complexity, process or novelty” (p.55) or “interested in learning about the participant’s psychological world” (p.66) and is said to be most effective when exploring fresh realisations about a particular phenomenon (Smith, 2008); all typical concerns of health psychology research. IPA is entirely congruent with the contemporary clinical and critical movements of patient-centeredness and acknowledging the voice of service users (Brocki & Wearden, 2006), and looks to understand health/illness experiences from the unique perspective of the experiencing individual (Pringle, Drummond, McLafferty & Hendry, 2011); balancing their representations against interpretations and contextualisation, and the potential influences of social and power relations (Larkin et al., 2006) and hence its applicability in the context of men and breast cancer.

Recognising the importance of adopting a reflexive attitude (Willig, 2013), IPA is also popular in health psychology because it involves participants reflecting on and making sense of their changed status in view of their illness experience (Hayton, 2009); thought to be beneficial for participants, enlightening both them and the researcher, and in facilitating change, often leading to explicit real-world applications (Shaw, 2010). Implications from IPA research are firmly rooted in the words or expressions of the participants, though the method does not deny the central role of the researcher in formulating IPA accounts (Pringle et al., 2011). While IPA researchers endeavour to stand in the shoes of their study participants, they also accept the impossibility of achieving direct access to another’s personal experience (Pietkiewicz & Smith, 2014); recognising that access depends on participants’ willingness to
disclose information, and that the process of making experiences and meanings comprehensible is complicated yet deepened by their own conceptions and active role within the research (Smith, Jarman & Osborn, 1999). Meanings are not transparent, and only through sustained engagement with and interpretation of participants experiential accounts are they made available to the researcher (Smith & Osborn, 2007). In acknowledging this, IPA provides a flexible framework for researchers trying to understand the meanings particular experiences hold for individuals (Smith & Osborn, 2007).

Although a contemporary formulation, IPA draws on theoretical ideas with much longer histories, influenced by the fundamentals of phenomenology, hermeneutics and idiography (Pietkiewicz & Smith, 2014); many of which were discussed 4.1.1 and 4.1.2. Described by Finlay and Ballinger (2006, as cited in Pringle et al., 2011) as ‘a variant of phenomenology’, IPA involves detailed examination of participants lifeworlds; the researcher accepting participants’ stories, while asking critical questions of their experiential accounts (Pringle et al., 2011). IPA is committed to exploring, describing, interpreting and situating individuals’ experiences in view of their unique context, examining every case in its own terms before producing a general account about the experiences of the study population as a whole (Pietkiewicz & Smith, 2014). Through interpretative activity, the researcher engages in a two-fold interpretation or ‘double hermeneutic’, attempting to make sense of the participants trying to make sense of their own experiences (Smith et al., 2009); shifting between emic and etic perspectives, evidencing both the participants and their own sense-making of the particular experience under investigation (Pietkiewicz & Smith, 2014).

According to Smith’s (1996) theorisations about IPA, the method also has theoretical roots in critical realism, symbolic interactionism and the social cognition paradigm, sharing a concern for the existence of real entities, meaning construction and mental processes; recognising that
humans are interpretive reflexive beings, and realising the complex connection between verbal accounts, cognitions and physical state (Fade, 2004; Smith & Osborn, 2007; Smith et al., 1999). Despite sharing a commitment to language and qualitative analysis, IPA’s concern with cognitions, sense-making and privileging the individual, separates it from other methodologies, offering a different perspective from approaches such as discourse analysis and grounded theory (Smith et al., 1999; Pringle et al., 2011). In comparison to other analytic techniques, IPA is said to allow “more room for creativity and freedom” (Willig, 2013, p.99), and is sufficiently flexible to engage with a diversity of data collection methods and knowledge bases; an epistemological openness that is unique and arguably a great strength of IPA (Larkin et al., 2006). This openness to different epistemologies and methods also suggests that IPA is perhaps better suited to mixed/multi-method research than other, less adaptive methods of analysis. Further, the adaptiveness of IPA is especially useful when the views of hard to reach populations are being sought (Pringle et al., 2011), as is often the case in CHP inquiries, and can also be argued in the case of men with breast cancer.

Semi-structured interviews tend often to be the choice method of data collection in IPA studies, described by Smith and Osborn (2003) as the ‘exemplary method’ for IPA, given that the technique shares several of its aims; including to gain the insider’s perspective and to work collaboratively with participants to achieve this (Brocki & Wearden, 2006). Semi-structured interviews also enable the researcher to engage with participants’ reflections, and to facilitate participants in giving voice in their own words; both of which are central premises of the IPA approach and critical qualitative research (Brocki & Wearden, 2006; Murray, 2015). Alternative methods of data collection have been used in published IPA work, including diaries (Smith, 1999), focus groups (e.g. Dunne & Quayle, 2001) and observational note-taking (e.g. Larkin & Griffiths, 2002), and there is also evidence of authors having previously used multiple qualitative data collection methods in the same IPA study (e.g.
Flowers, Duncan & Knussen, 2003; Williamson, Leeming, Lyttle & Johnson, 2012). While IPA is typically applied to verbal and textual data formats, according to Brunsden (2015), it can also be used well on visual images. A number of health/illness-related studies have previously employed Photovoice-style methods to enrich phenomenological inquiry, applying various forms of analysis, including IPA; a few examples of which have recently emerged in health literature (e.g. Capewell, 2015; Davtyan & Brown, 2015; Jones, Ingham, Cram, Dean & Davies, 2013). There is also evidence, albeit limited, of studies specifically combining semi-structured interviews with photographs and IPA, e.g. Williams, Morrison & Robinson (2013); further demonstrating IPA’s compatibility with both methods of data collection and multi-method research, and thus the methodological approach to this research.

In terms of sampling, IPA studies typically aim for a relatively homogenous sample so that convergence and divergence of individuals’ experiences within the sample population can be studied in depth; hence, study samples tend to be selected purposely (Smith et al., 2009). In the same way that there is no prescriptive way of conducting IPA, there are also no rules with regards to sample size (Pietkiewicz & Smith, 2014), though typically the method is conducted with smaller samples; breadth sacrificed for depth owing to the idiographic commitment of IPA inquiry (Smith & Osborn, 2007). As Brocki and Wearden’s (2006) review of IPA research highlights, participant numbers in published papers vary considerably; ranging from single-case studies (e.g. Robson, 2002) to analyses of small (e.g. Johnson et al. 2004, N=6) and medium-sized groups (e.g. Turner et al., 2002, N=12), and occasionally much larger samples (e.g. Reynolds & Prior, 2003, N=35; Murray, 2004, N=35). So, while it is less common, IPA is indeed possible with larger sample sizes (Pietkiewicz & Smith) and is therefore suitable for employment in qualitative PhD studies which, on average, tend to include around 30 study participants (Mason, 2010). Still, some scholars argue against using IPA with larger samples (e.g. Smith & Osborn, 2003), claiming
that researchers – particularly novices – can become overwhelmed by large qualitative datasets and, as a result, do not do data justice. Doing IPA even with a small sample is a “demanding enterprise” for researchers (Pietkiewicz & Smith, p.13), as realising the potential of each case is an intense, time-consuming and challenging task (Smith et al., 2009), and arguably even more so when multiple data formats are involved (Brocki & Wearden, 2006). Nevertheless, providing that full appreciation is given to each individual account, and that the researcher can produce a comprehensive and in-depth analysis about the particular experience under investigation, IPA need not be confined for use only with small samples.

Having considered its central premises, theoretical foundations and how it serves qualitative inquiry, IPA then presents as a suitable method of analysis here for several reasons. Not only do the primary concerns of IPA meet with those of the current research, i.e. to explore in depth first-hand accounts of a particular experience, and to give voice to members of the study population, the method shares similar theoretical roots too; also informed by phenomenology, hermeneutics and critical realism. Participant-centred, privileging the individual and sufficiently adaptive to be able to engage with hard to reach populations, and both established (e.g. semi-structured interviewing) and innovative (e.g. visual techniques) data collection methods; IPA demonstrates applicability to critical qualitative approaches as well as mainstream psychology, and is particularly suited to inquiries with a health/illness focus. Further, despite appearing less frequently in multi-method research and alongside visual methods and larger samples, there are published studies that evidence and advocate such applications of IPA. Thus, given its fit with the intentions of this inquiry, IPA is the choice method of analysis.
4.5 Chapter summary

This chapter has introduced the methodological thinking behind and approach to the second half of this two-part inquiry; outlining the multi-method strategy that is employed in view of ontological and epistemological considerations (4.1); also, the challenges and opportunities of methodological pluralism (4.2). It has also detailed the chosen methods of data collection and analysis (see 4.3 & 4.4) and explained their applicability to the line of inquiry. The case has been made that the epistemological and ontological fusion of critical realism, phenomenological psychology and PR within a CHP framework is both suitable and justified (see Figure 2, p.62) relative to the study of men and breast cancer, and specifically the aims of the current research. It is argued that combining these separate yet related philosophical bases affords the potential for greater insight and a more comprehensive understanding of men’s breast cancer experiences than a mono-methodology would achieve in this context. In Chapter 5, a description of how the chosen methods were practiced is presented.
Chapter 5 – Method

As mentioned earlier in Chapter 4, which presented the research methodology, situated within a CHP paradigm (Chapter 4, Figure 2) and following on from the qualitative synthesis (Chapter 3), the second half of this two-part study is a multi-method qualitative inquiry, combining verbal and visual accounts of men who have experienced breast cancer (MEBs); recruited by diverse means using diverse methods. Complementing Chapter 4, this chapter provides further methodological and ethical details pertaining to this second study phase. Specifically, Chapter 5: discusses recruitment and sampling considerations (5.1); situates the sample by detailing information about the study participants (5.2); outlines the materials and equipment used to gather data (5.3), and the study procedure (5.5); explains the centrality of ethics and relative ethical conduct (5.4); and, describes the analytic strategy employed (5.6). Methodological reflections are presented later in Chapter 9 (9.9.2).

5.1 Recruitment and sampling

5.1.1 Sampling considerations

5.1.1.1 Inclusion criteria

Sampling was purposive since the study intended to specifically represent the voice of men who had received a formal breast cancer diagnosis. Inclusion criteria prescribed that all participants would be men of adult age, i.e. 18+ years, so as to provide their own consent; fluent in both written and verbal English, to ensure full understanding of the research and any related study materials; and, clinically diagnosed with breast cancer after 1995, allowing for an exploration of men’s accounts at various points of their cancer autobiographies over a 20-year timeframe (the interview schedule adapted accordingly). All men who met with these criteria were considered for inclusion.
5.1.1.2 Sample size

Numerous factors can determine what constitutes a sufficient sample size in qualitative studies (Baker & Edwards, 2012); thus, there is no definitive number (Smith & Osborn, 2003). Researchers who adhere to traditional qualitative research principles argue that sample size should be determined by saturation, i.e. when data fail to yield new information (Glaser & Strauss, 1967), while some contemporary researchers challenge this concept (e.g. Dey, 1999), suggesting that the point of saturation is elastic and an impractical measure. Further, saturation is not typically used in IPA research, which is cautious about claims to transferability. Unorthodoxically, some researchers have offered guidance on determining sample sizes for different qualitative methodologies (Guest, Bunce & Johnson, 2006). For example, regarding phenomenology, Creswell (1998) suggested 5-25 interviews, while Morse (1994) advised between 30 and 50 interviews for ethnographic research. In traditional Photovoice studies, samples tend to be smaller, with 7-10 participants recommended for practical analysis (Wang, 1999). However, previous studies have successfully employed Photovoice-style methods with larger samples; some of which focused explicitly on cancer-related populations (e.g. Lopez, 2005, N=13; Oliffe, 2007, N=19). Further, in their review of 37 Photovoice studies, Catalani and Minkler (2010) found no relationship between sample size and quality of participation to suggest Photovoice, or Photovoice-inspired methods, are restricted for use only with small study samples.

Regarding the analytical method, as earlier discussed in Chapter 4 (4.5), given the central tenets of IPA and what the method aims to achieve, studies analysed by way of IPA typically operate smaller sample sizes. However, as with Photovoice, there is a body of existing research within health psychology demonstrating the use of IPA with larger samples and justifying such applications of the method (e.g. Reynolds & Prior, 2003; Murray, 2004),
providing that the mode of inquiry remains idiographic and the sample relatively homogenous (Smith & Osborn, 2003), as it does in this study.

Sample size is also contingent on the broader purposes of the research; thus, that this research was primarily conducted in fulfilment of a PhD programme of research must also be considered. Mason (2010) investigated sample sizes in qualitative research specifically in relation to PhD studies. Findings revealed an average sample size of 31 in over 550 PhD studies using various qualitative approaches where interviews were the choice data collection method. In view of Mason’s findings and having considered the sample sizes of other studies employing the same/similar methods, the aim was to recruit a sample of 30-32 men, with at least 20 of these men participating in visual voice interviews, to justify the multi-method approach employed (see Chapter 4).

5.1.1.3 Inclusivity and diversity

As noted earlier in the qualitative synthesis (see Chapter 3), previous research exploring breast cancer in men has tended to employ small unrepresentative samples lacking cultural and ethnic diversity and demonstrates little evidence of recruiting men from BAME and non-heterosexual populations. Further, participants were generally recruited from volunteer populations, suggesting that the findings to date reflect only a subset of the target population (Boughner, 2010), failing to represent the wider male community affected by breast cancer.

In an effort to address these sampling limitations of earlier works, and in view of the CHP approach adopted, men were strategically recruited so as to engender a more inclusive study sample, and thus, outcomes with greater diversity. Participants were therefore recruited via both NHS and non-NHS means; this dual approach serving to both maximise recruitment potential and diversify the study sample. Ethnic minority men within the population group were also approached through targeted recruitment (see 5.1.2.2.2).
5.1.2 Recruitment strategy

Table 3. Overview of Key Recruitment Information

<table>
<thead>
<tr>
<th>Participation Type</th>
<th>NHS-England</th>
<th>Print Media</th>
<th>Social media</th>
<th>Breast Cancer Care</th>
<th>Public &amp; private sectors</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual voice</td>
<td>6</td>
<td>3</td>
<td>9</td>
<td>2</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Verbal-only</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Total No. Recruited</td>
<td>10</td>
<td>6</td>
<td>10</td>
<td>5</td>
<td>0</td>
<td>31</td>
</tr>
</tbody>
</table>

Key recruitment information is presented above in Table 3. The approach taken to recruiting participants varied both across and within the two recruitment streams, categorised as NHS and non-NHS, according to how the men were sourced, as will now be discussed.

5.1.2.1 NHS recruitment

Participants sourced through the NHS were recruited via a breast care centre at a large hospital in the English Midlands; selected on the basis that it sees the largest number of male breast cancer patients of all the NHS breast centres UK-wide (typically treating between 1-4 men annually), and also because it has an ethnically diverse patient population. The centre has access to a comprehensive patient database with diagnostic and treatment data held for every patient treated at the centre, dating back to 1997. As NHS ethics did not permit the researcher access to patient records, a search of this database was conducted on the researcher’s behalf by the centre’s Head of Service and her staffs. A database search of current and past patients initially identified 61 potential participants; however, 42 of those were found to be deceased, and one additional man who was not yet on the centre’s database presented during the recruitment period, yielding a final number of 20 eligible participants.

Study information packs (including the Participant Information Sheet (PIS), ‘Photovoice’ guide and study invitation with reply slip and pre-paid envelope) were sent out from the
breast care centre to all 20 men, on the researcher’s behalf. Packs were distributed in two waves (10 in each wave), sent exactly one month apart to steady the inflow of replies being returned to the centre, managed by the medical secretary. The secretary’s role was to collect, sort through and collate the replies into Yes/No groupings, providing the researcher with only the contact details of interested individuals. The secretary also maintained a list of which men had been contacted on what dates and who had replied, enabling reminder letters to be sent out to all men marked as ‘still to reply’ one month after sending the initial communication. Where no reply was received to either correspondence within the allotted timeframe, i.e. two months from the initial invitation, participants whose replies were outstanding received a telephone call from the secretary to confirm receipt of the letters, and to establish their participation decision. Interested individuals thereon in liaised directly with the researcher.

Of the 20 men identified through the database search, half agreed to take part in the study. All 10 men contributed data; six providing verbal-only accounts, four participating in visual voice interviews. Eight men formally declined the invitation to participate, while two men did not reply to any communications sent to them from the breast care centre.

5.1.2.2 Non-NHS recruitment

Participants recruited beyond the NHS were sourced through multiple means, including: third-sector organisations, public and private sector corporations, print media and social media platforms. Organisations were approached in a staggered fashion, allowing for a steady recruitment flow while avoiding a clustering of interviews. Some men came to know about the study via several different sources, though every effort was made to prevent men receiving repeat invitations where possible. Recruitment strategy for the non-NHS stream is discussed below according to each of the means utilised.
5.1.2.2.1 Print Media - Newspaper articles

Several men were identified as potential participants owing to them appearing in newspaper articles focused on breast cancer in men, or more commonly, a feature specifically about them and their personal breast cancer experience. Two articles of this nature (see Leek and Post Times, 2014; Telegraph, 2014) went to press around the time that data collection commenced, leading the researcher to search for other similar articles; a number of which existed in the online archives of various local and national newspapers. The articles included much detailed information about the men featured, enabling the researcher to search for these men using the British Telephone directory and/or online directory enquiries services. Contact details for several of the men were established through this process. These men were then approached by telephone or postal communication depending on the contact information available; the researcher explaining first how they had identified the individual, before informing them about the research and inviting them to take part. Interested individuals were then sent the study information pack by email or post depending on their preference and asked to reply within one month indicating their participation decision. The reminder letter was issued to individuals that did not reply within the specified timeframe, and if no reply was received to either correspondence, it was assumed that participation was declined.

Nineteen men were identified through newspaper publications, though two of these men were deceased; the articles reporting on them posthumously. Contact details were obtained for 11 of the surviving men identified; six of whom contributed data: three visual voice accounts and three verbal-only (see Table 3).

5.1.2.2.2 Third-sector organisations

Many third-sector and charitable organisations were approached to request their assistance in recruiting prospective participants; typically, by email and/or telephone in the first instance,
though occasionally in-person at local offices. As the target population was UK men, only UK organisations were contacted. Elected organisations were chosen based on their relevance to the study topic, i.e. men’s health, breast cancer and/or cancer-focused corporations, and/or those attracting predominantly male audiences. The size and scale of these agencies varied considerably, ranging from large national organisations (including, Breakthrough Breast cancer, Cancer Research UK, Genesis, The Haven, The Institute of Cancer Research, Macmillan Cancer Support, The National Cancer Research Institute, and The Royal British Legion.), through international supports (i.e. Maggie’s Centres), to local charities operating on a much smaller scale (i.e. The Big C Cancer Charity, Coping with Cancer, Derby Breast Cancer Support, GEMS Charity, Hope Against Cancer, Men’s Health Forum, The Lily Centre and LOROS). In the interest of equality, a number of organisations specifically intended for persons belonging to ethnic and sexual minority groups were also approached (i.e. Age UK’s Leicester Black and Minority Ethnic Elders, Cancer Black Care, Cancer Equality, Macmillan Cancer Support, MOSAM BME cancer support, Out with Cancer and the Midlands Gay, Bi and Trans Cancer Support Group). Of the numerous organisations contacted, participants were only recruited directly from one organisation: Breast Cancer Care (BCC).

Having previously assisted earlier PhD researchers with the recruitment of men (e.g. Halls, 2013), BCC was identified early on in the research process as a key organisation to approach when recruiting study participants beyond the NHS. Initial contact was made with the charity following an article published in the local press in October 2014 as part of breast cancer awareness month; this featured a local man who had recently become a patient mentor for the charity, following his own breast cancer experience. An email was sent to BCCs head office referencing the news article, requesting that the man featured, and other men alike, be informed about the research and provided with the researcher’s contact information. The
email also explained how it was hoped that the featured man, as an experiential expert located close to the researcher, would serve as both a participant and research partner; acting as an advisory aid insofar as evaluating the proposed research design and interview questions prior to commencing data collection, to which he agreed. This is consistent with CHP and PR, situating participants as co-researchers in the research process (see Chapter 4 – 4.1.2); though on reflection, the research did not fully realise this collaborative endeavour (see Chapter 9.5).

Emails were initially sent out from the facilitating BCC branches on behalf of the researcher to volunteers within those regions; interested individuals were requested to contact the researcher direct for further information and/or to arrange participation. Subsequently, five men self-selected to take part, all of whom contributed data: two participating in visual voice, three providing verbal-only accounts (see Table 3).

5.1.2.2.3 Public and private sector organisations

A number of public and private sector organisations were also approached. Public organisations included men-focused societies, e.g. Working Men’s Club and Institute (CIU), and appropriate trade unions: Hospital Consultants and Specialists Association (HCSA), Public and Communications Services Union (PCS), UNISON, Union of Construction, Allied Trades and Technicians (UCATT), and University and College Union (UCU). Privatised organisations ranged from local and national level sporting associations, e.g. Leicester City Football Club, The Football Association, etc., to private healthcare services, e.g. Spire Healthcare.

The decision to approach public and private sector organisations to assist with recruitment was based upon several factors. First, their potentially wide-reaching capabilities; large organisations with sizeable workforces/member numbers were specifically targeted since they demonstrated potential to advertise the research to wider, more diverse audiences.
Second, thinking ‘out-of-the-box’; recruiting men beyond breast cancer and men’s health arenas via these such channels importantly reached out to men who ordinarily might not position themselves as research volunteers. And third, accessing the target population; since most of the third-sector organisations contacted had predominately female members and service users, male-dominated public and private organisations were targeted.

More than 25 organisations were approached from across the two sectors, though only five replied to the request for their assistance (one public, four private). One organisation declined; however, four organisations (i.e. Leicester Riders, Northampton Saints, Notts County Football Club, and the Working Men’s Club and Institute (CIU)), agreed to assist recruitment by sharing the study flyer with their members in hard copy and/or electronic formats, including email and social media notifications. Despite these efforts, the public and private sector recruitment drive failed to yield any study participants.

5.1.2.2.4 Social media platforms

As Mendelson (2007) points out, people are increasingly turning to online services for information and support about health and illness experiences, as are health and illness researchers, who are increasingly using online communities to recruit targeted research participants and more diverse inclusive samples. Research (e.g. Close, Smaldone, Fennoy, Reame & Gray, 2013; Fenner, Garland, Moore, Jayasinghe, Fletcher, Tabrizi et al., 2012) has previously advocated the use of online social network sites to recruit research participants, expressly those belonging to hard-to-reach populations; e.g. minority groups, such as men with breast cancer. Boyd and Ellison (2008, p.211) define social network sites as:

“web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made
by others within the system. The nature and nomenclature of these connections may vary from site to site”.

People’s motivations for participating in social media platforms are diverse and wide-ranging (Brandtzaeg & Heim, 2009), and arguably even more so during an episode of ill-health (Himelboim & Han, 2013; Koskan, Klasko, Davis, Gwede, Wells, Kumar et al., 2014). With more UK adults, particularly older adults (65+), now going ‘online’ and using social networking sites than ever before (Ofcom, 2014); given the typically older onset age of breast cancer in men, the small population size of MEBs, and the potential to reach out to a wider male audience, social media platforms were considered plausible means by which to recruit prospective participants beyond the NHS.

Four online networks, including three social networks and one professional network site, were used to publicise the research: Twitter, Facebook, LinkedIn and Instagram; chosen based on their great numbers of active and diverse members, and the researcher’s user ability on these sites. Although the researcher already held personal accounts for all of these sites, in the interests of researcher safety and professionalism, new study-specific user accounts were generated for each of the sites. As social media was neither the only, nor the primary recruitment source, generating basic free-to-use accounts for each platform was deemed sufficient. Each online profile included the same information: the researcher’s name, academic institution, professional status and research interests, along with a recent photograph of the researcher for the required profile picture. To ensure that the information shared via social media was well-publicised, privacy settings for all accounts were set at the minimum level; enabling all users of the individual sites to potentially view all communications posted to the separate online arenas. The approach to and use of the elected social network sites was variable, with recruitment strategy largely dependent upon the
operations and constraints of the individual platforms. The number of men recruited via social media and the breakdowns for each individual site are presented in Table 4.

Table 4. Participants Sourced Via Social Media (k=10)

<table>
<thead>
<tr>
<th>Participation type</th>
<th>Facebook</th>
<th>Twitter</th>
<th>Linked in</th>
<th>Instagram</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual voice</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Verbal-only</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total No. of men recruited</td>
<td>6</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

5.2 Participants

As Elliott, Fischer and Rennie (1999) noted, situating the sample, i.e. giving details about the study participants, is an indicator of good quality qualitative research; helping the reader to better understand “the range of persons and situations to which the findings might be applicable” (p.221). All participants were biologically born men, who had received a clinically confirmed breast cancer diagnosis between 1995 and 2015. Breast cancer was the primary cancer diagnosed for all participants, though three men had also developed secondary cancer (see Table 6). The participant furthest beyond receiving their primary diagnosis was 19 years post-diagnosis, while the most recent diagnosis recorded was seven months prior to participation. Thirty-one men were recruited from across the UK; 10 men were sourced through the NHS, and 21 via non-NHS means (see sections 5.1.2.1 & 5.1.2.2). Twenty men consented to taking part in visual voice, while 11 opted to provide a verbal-only account of their breast cancer experience. Participants predominantly identified as White-British, heterosexual, married men, and were most commonly aged between 50-59 years at diagnosis (see Table 5). The oldest participant at the time of interviewing was 89 years of
age, and the youngest, 47. Further, one participant was profoundly deaf. At the time of their participation, most men were retired; some had returned to work following the breast cancer episode, while two had subsequently become unemployed. Key demographic characteristics of the study sample are presented in Table 5.

With regards to clinical care, treatment for the majority of participants was provided by the NHS. Only four men sought private medical care. Two of these men received combined care from both the NHS and private services; though one of them chose to transfer back to solely NHS care after initially opting for private-only treatment. All participants underwent surgical treatment for their breast cancer. Mastectomy (breast removal) was the most common surgical procedure prescribed, with the majority of participants undergoing a single mastectomy (see Table 6). Mastectomies were primarily carried out as a curative treatment method, though three men elected to have a mastectomy to prevent future cancer recurrence in the breast(s). Treating breast cancer solely by surgical means was only possible for three of the men interviewed. The majority required further clinical intervention, typically, anti-cancer drugs and/or radiation treatment followed by hormone therapy; a precautionary measure used with hormone-receptive breast cancers to lower the risk of breast cancer recurrence. A combination of chemo- and radiotherapies were prescribed for most participants, though some were prescribed either-or treatment. Hormone drug therapy was recommended for most men, with Tamoxifen (an oestrogen inhibitor) the most commonly prescribed drug; participants typically taking the medication for 5+ years, though closer to 10 years in some cases. Some men were initially prescribed Tamoxifen, but later switched to an alternative hormone drug under clinical guidance (Anastrozole or Letrozole, see Table 6). One man refused hormone therapy, due to concerns over related side-effects. At the time of their participation, 14 men were still receiving some form of clinical treatment for their breast cancer.
Regarding after- and follow-up care, none of the men interviewed had undergone reconstructive surgery of any kind at the time of their participation; 17 men had discussed reconstruction options with their clinicians, but 14 men said reconstruction was never offered to them. Some men reported seeking professional psychological support for their breast cancer, though most chose not to access formal support services. Only three men had attended a support group; only one of which was breast cancer specific. A small number of men also explored the use of complementary and alternative therapies (CAMs). Further details of key illness-specific information are presented in Table 6.
### Table 5. Demographic Characteristics of The Study Sample

<table>
<thead>
<tr>
<th>Age at Diagnosis</th>
<th>Ethnicity (Self-specified)</th>
<th>Marital Status</th>
<th>Employment Status</th>
<th>Sexual orientation</th>
<th>Years survived since initial breast cancer diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Age groups</td>
<td>White British</td>
<td>White Irish</td>
<td>White Scottish</td>
<td>White Welsh</td>
</tr>
<tr>
<td>40-49 Years</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>50-59 Years</td>
<td>13</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>60-69 Years</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>70+ Years</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Totals</td>
<td>29</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>

### Table 6. Illness-Specific Information

<table>
<thead>
<tr>
<th>Surgical treatment</th>
<th>Anti-cancer treatments</th>
<th>Hormone therapy</th>
<th>Professional psychological support</th>
<th>CAMs</th>
<th>Developed secondary cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single Mastectomy</td>
<td>No surgical treatment</td>
<td>Chemo-therapy</td>
<td>1-2-1 support (Counselling)</td>
<td>Engaged with online services</td>
<td>No known secondary cancer</td>
</tr>
<tr>
<td>Double Mastectomy</td>
<td>Chemo-therapy</td>
<td>No anti-cancer treatment</td>
<td>No formal support</td>
<td>Dietary changes</td>
<td>Lung Cancer</td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>Radiotherapy</td>
<td>Tamoxifen only</td>
<td>No hormone treatment</td>
<td>Acupuncture</td>
<td>Bone cancer</td>
</tr>
<tr>
<td>No surgical treatment</td>
<td>Chemotherapy combined</td>
<td>Anastrozole</td>
<td>Letrozole</td>
<td>Reiki</td>
<td>No exploration CAMs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No hormone treatment</td>
<td>Attended support group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>29</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>

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5.3 Materials and equipment

5.3.1 Study materials

Twelve items were generated specifically for the study. Copies of the ‘interview schedule’ and ‘Photovoice’ interview prompts are provided in the appendices (see Appendix A & B). Clean copies of all other study materials are available on request.

*Study Flyer;* designed to advertise the research and aid recruitment, this briefly outlined the purpose of the research, the inclusion criteria, and the researcher’s contact details. The flyer was produced in several formats: circulated online as a JPEG image file via e-mail, web pages, and social media postings; printed and displayed as an A4-sized poster on yellow-coloured paper (chosen for its gender neutrality); also, as an A5-sized leaflet (also printed on yellow paper) that interested individuals could read and respond to.

*Study Invitation Letter;* the initial communication sent out to all prospective participants explaining the purpose of the research, what participation involved, why they had been invited to take part, and how to register (or decline) their interest.

*Study Reminder Letter;* issued only to participants who did not respond to the *Study Invitation Letter* within one month of the communication being sent, designed to prompt individuals to return outstanding replies.

*Participant Information Sheet;* a detailed 5-page document that fully explained the research and participation process, ensuring that prospective participants had sufficient knowledge to inform their participation decision.

*‘Photovoice’ Guidance for Participants;* outlined the visual voice component and why the method was selected, what ‘Photovoice’ entails and how participants’ photographic data would be used.
‘Photovoice’ Camera Instructions; a ‘How-To’ guide for participants who opted to use the single-use/disposable camera offered by the researcher to those participating in visual voice. (Note: this document was in fact surplus to requirements, as all participants used their own devices).

Consent Form; 15 statements about the research which participants were required to read and initial to indicate their understanding and agreement, confirming their decision to participate. Participants were required to complete and sign two copies of this form, retaining one copy for their own records.

Demographic Questionnaire; a brief 3-item non-validated questionnaire developed specifically for the study. Items refer only to participants’ demography, specifically: age, preferred self-described ethnicity, and marital status.

Interview Schedule; 20 topical questions generated in view of both earlier research findings and new avenues of interest, serving as an aide-memoire for the researcher to support interview discussions as required. Sample questions taken from the interview schedule include: “What would you say are the main challenges or frustrations of living as a man with breast cancer?” and “How has your breast cancer experience affected the way that you see yourself, your life or the world more generally?”

‘Photovoice’ Interview Prompts; similar to the interview schedule, five prompts were developed by the researcher to aid the discussion of participants’ photographs. Sample prompts include: “Describe to me what is going on in this photograph?” and “Why did you select this particular image?”

Thanks and debriefing sheet; issued to participants at the close of the interview, thanking them for their participation and also documenting some further information including: a brief
summary of the research, next steps (in terms of the data provided), and references for relevant professional support services should further support be required post-participation.

Confidentiality declaration; issued to persons who assisted the researcher with data transcription, this form contains a series of statements that the transcribers had to initial and sign their agreement with prior to working with any study data.

5.3.2 Equipment

All online interviews were conducted using Skype™ (downloaded from www.skype.com/en); a freeware program that permits audio and video communication over an internet protocol. All interviews were audio-recorded using a digital dictation device to enable playback of the recorded interviews for transcription purposes. Details of all equipment and the models used are available on request.

A Fujifilm QuickSnap single-use/disposable camera was offered to all participants who opted to take part in visual voice. However, all participants chose to record their photographs using their own camera device; usually a smartphone or tablet with built-in cameras.

5.4 Ethics

Ethical conduct and standards were adhered to in line with the British Psychological Society's most recent guidelines for principled research involving human participants (BPS, 2004; 2009; 2014). Gaining ethical approval was a three-arm process, with permissions required from the University, the Health Research Authority (HRA), and the appropriate NHS Trust. Recruitment via the NHS could not commence without approval from all three arms. For recruitment beyond the NHS, ethical approval from the University was regarded as sufficient.

Internal approval from the University was granted by the Faculty of Health and Life Sciences Research Ethics Committee (HLS-FREC). The application was submitted on 1st May 2014,
and approval was granted without need for any amendments on 19th May 2014. Next, the necessary external approvals were sought from a local branch of the National Research Ethics Service (NRES), and the appropriate NHS Research & Development (R&D) team linked to the NHS Trust covering the NHS site being accessed, i.e. the breast care centre (all of which are governed by the HRA). Approval was confirmed by a local NRES ethics committee on 6th November 2014, and R&D approval was formally granted on 10th June 2015, with permission to recruit participants via the breast care centre authorised until 31st October 2016.

5.4.1 Ethical considerations

Defined by “a rights- and an ethics-based premise”, and engaging “with issues of justice and fairness” (Hepworth, 2006, p.339), one of the primary goals that CHP sets itself is to promote and uphold the highest possible ethical standards; since its “enduring vision of health is one intrinsically linked with equality” (p.334). Therefore, as a critical health inquiry, the current study also adhered to highest ethical standards and conduct. The potential for ethical issues pertaining to each of the following aspects was considered in detail: anonymity, approaching and the recruitment of participants, confidentiality, consent, data protection and storage, debriefing, researcher competence, risk to participants and the researcher, and withdrawal of data and participation. In addition to standard ethical considerations relating to these matters, study-specific aspects were also addressed.

5.4.1.1 Participation preferences

Consistent with the CHP approach to the research, participants were afforded various choices regarding their participation. With regards to upholding anonymity, participants could either choose their own pseudonym or elect for the researcher to assign them a study alias. In critical health inquiries, participants are often given the option of using their real name in keeping with the concept of participants owning their own voice; however, the stringency of NHS
ethics vetoed this, so for consistency all participants names were pseudonymised. Relatedly, as some terminologies associated with cancer can be deemed offensive (e.g. the term ‘Male Breast Cancer’ for some needlessly differentiates men), participants were also consulted on how they should be referred to as a collective in the writing up of the research. Most opined that ‘Patients’ was not inclusive of those no longer receiving treatment, and many disliked the term ‘Survivor’ for multiple reasons, e.g. to be ‘in remission’ does not assure survival. After discussions with study participants, and members of relevant social media groups, the term ‘Men who have experienced cancer of the breast’ or ‘MEBs’ was agreed on as a suitable phrase/acronym to reflect the research participant group.

Participation preferences also extended to how the interviews were conducted. Participants could choose to be interviewed either: in-person, at their home address or at the University; online, via an internet protocol using microphone and web-camera devices; or by telephone. Further, in order for the research to be as inclusive as possible, one man, whose deafness prevented him from being audio interviewed, participated by providing a written response to the interview schedule questions. In addition to electing how they were interviewed, participants also had choice regarding the type of interview they participated in; able to opt-out of providing the photographic account if they preferred, thus still making participation possible for those unable and/or reluctant to engage with visual voice.

Those participating in visual voice were given the choice between using a single-use/disposable camera provided by the researcher, or their own camera device. Participants were advised to safeguard any digital data recorded using password-protection, especially smartphone users, and advised on how to share their visual data with the researcher securely. All participants were requested to record their photographs over a two-week period, and to submit them to the researcher one-week ahead of their scheduled interview date for printing
and safe storage. Participants decided how many photographs they contributed, and the order in which they were discussed; they were also asked to give each image a title or short caption, ensuring that all textual aspects of the accounts given were always the words of the participant.

5.4.1.2 Ensuring consistency

Given the different recruitment streams and methods of interviewing employed, ensuring consistency in the treatment of participants was imperative. Irrespective of the means by which participants were interviewed, all were required to complete and sign the consent form before the interview could commence; online and telephone interviewees returning their forms by email. Participants understood that all interviews would be audio-recorded to enable verbatim transcriptions post-interview, and all were provided with the written debriefing document at the close of the interview (online and telephone interviewees receiving this by email). All study documents were standardised; however, compliant with the requirements of NHS R&D, all documents provided to participants sourced through the NHS had to be printed on letter-headed paper specific to the enabling site, i.e. the breast care centre. Use of this letterhead was not permitted where participants were recruited beyond the NHS site, therefore all documentation received by non-NHS recruits was printed on plain white paper; the content though, unchanged.

With regards to approaching prospective participants, procedures recommended for recruiting via the NHS were also followed for non-NHS recruitment, i.e. all participants received one study invitation, followed by a single reminder about the study if no reply was received within one-month of the initial communication. Where participants expressed an interest but communication subsequently went ‘cold’, the researcher attempted to contact these
individuals on two further occasions; if no reply was received after the second attempt, communications initiated by the researcher then ceased.

5.4.1.3 Photo-based considerations

As breast cancer is a sensitive topic, photo-taking ethics and the potential for the photographic account to affect participants’ self-perceptions were key considerations. Participants were not expected to photograph themselves or their bodies, though this was not prohibited, and were explicitly asked not to take photographs of other persons, especially minors. Likewise, participants were advised not to photograph places/organisations without seeking relevant permissions first. Issues relating to authorship and ownership of photographs were also considered. Participants were advised that only photographs taken by themselves or on their behalf for the purpose of the study should be used; all other photographs required permission from the author of the image, due to the resultant shared ownership (between the author and researcher) of all photographic data contributed to the research (see Tinkler, 2013).

Though not an initial consideration, giving participants free-rein regarding compilation of their photographic account resulted in many participants using a combination of solicited and unsolicited photographs. Some also generated their images by photographing existing photographs. The appropriateness of participants making use of images originally intended for other purposes was carefully appraised by the researcher and participant collectively, and providing relevant ethical aspects were adhered to, permitted.

5.4.1.4 Upholding confidentiality

Due to the volume of data generated by the interviews and time constraints of the PhD, it was necessary for the researcher to seek some assistance with data transcription. Individuals who assisted with data transcription were required to sign a confidentiality agreement prior to any
data being shared and were given instructions on data handling during their involvement with any data accessed.

5.4.1.5 Risk assessment

Potential risks to the participants and the researcher were carefully considered. To safeguard participants (and satisfy NHS R&D), the researcher had to obtain clearance from Disclosure and Barring Services (DBS), complete NHS training sessions for ‘Good Clinical Practice (GCP1)’ and ‘Consent for Research’ and undergo physical and psychological health assessments to assure good health. The researcher was also required to wear photo ID (produced by the University) for every interview conducted. Participants’ welfare post-participation was also considered; the debriefing document providing contact information for two well-established breast cancer support services in case participation raised any concerns and/or additional support was required.

To ensure the safety of the researcher, a lone-working agreement was devised whereby the researcher would elect a nominated individual (usually the first supervisor) to call/text on arrival and exit of every interview conducted in-person. This procedure was essential where interviews took place at a participant’s home, but also adhered to for interviews carried out at the University. The researcher shared no personal contact information with participants; a study-specific mobile phone number was set up and used for all telephone-based communications, and new social media and Skype accounts were purposefully generated for web-based interactions. All email communications were sent from and received to the researcher’s University email account, which belongs to a protected online system. All postal communications were addressed from and to the University, or, if relating to NHS recruitment, the breast care centre. Any specific causes for concern raised by the researcher were discussed with the research supervisory team as soon as possible post-interview.
5.5 Procedure

Thirty-three interviews were conducted by the researcher with 31 men over a 12-month period, from December 2014 to December 2015. All but one interview was conducted face-to-face and in-person, the majority of which were carried out at participants’ homes; though some were conducted on-campus at De Montfort University, and online via Skype, and one by telephone (see Table 7). Most interviews were a single event; however, two participants did request to split their interview into two parts, providing their verbal and visual accounts separately over two interviews at different time points. The majority of interviews were conducted 1-2-1, though in some cases (five), participants requested that their spouse/partner be present too. All interviews were performed in a quiet, confidential space, and audio-recorded for transcription purposes post-interview. The shortest interview was 1 hour and 7 minutes in length; the longest lasted for 3 hours and 25 minutes.

Table 7. Type and Nature of Interview

<table>
<thead>
<tr>
<th>Interview Type</th>
<th>Nature of Interview</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>In-Person</td>
<td>Skype</td>
</tr>
<tr>
<td>Participants home</td>
<td>University campus</td>
<td>Video-enabled</td>
</tr>
<tr>
<td>Visual voice</td>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td>Verbal-only</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Total No. of Interviews</td>
<td>23</td>
<td>7</td>
</tr>
</tbody>
</table>
All prospective participants, irrespective of the recruitment means, were sent the ‘study information pack’ which included: A Study Invitation Letter (with reply slip), Participant Information Sheet, ‘Photovoice’ Guide, and a stamped addressed envelope for those recruited by postal communication. Recipients were instructed to read the enclosed documents and to indicate their participation decision by completing and returning the reply slip in the envelope provided. Non-NHS recruits could also reply by email if preferred. Participants were asked to reply within one-month of receiving the study invitation. If after this time frame no reply had been received, the Study Reminder Letter was issued to the individuals concerned, giving them a further three weeks to return their participation decision. If no reply was received to the reminder communication, it was assumed that the opportunity to participate had been declined. All non-NHS replies were handled by the researcher; however, only positive replies from NHS recruits were forwarded to the researcher for their attention.

Interested individuals were contacted direct by the researcher to arrange their participation, by telephone and/or email. It was assumed that all participants would be interviewed in-person and take part in visual voice, unless participants requested to be interviewed online or by telephone and explicitly opted out of contributing photographic data. Visual voice participants were requested to take around 5-10 photographs relating to their breast cancer experience, using either the single-use camera obtainable from the researcher, or their own camera device. Participants typically recorded and gathered their photographs over a two-week period, though some took longer where necessary depending on their individual personal and/or health circumstances. Once they had taken their photographs, participants were asked to submit copies, along with a title/short caption for each image, to the researcher for printing ahead of their scheduled interview. All participants received a telephone call from the researcher the day before their planned interview to confirm their pre-arranged participation.
and the agreed time and interview location. At the interview, prior to beginning, participants were asked to read initial and sign two copies of the consent form, retaining one copy for themselves; this was followed by completion of the demographic questionnaire. Next, visual voice participants were presented with their printed photographs, asked to confirm the accompanying titles/captions given and to number order their images, if an ordered discussion was preferred. Participants then decided how to include their photographs as part of the discussion, choosing from: beginning with the images, discussing them alongside questions from the interview schedule, or lastly, after the questions.

To assure functionality of the recording device, before starting the interview, the researcher first asked participants to answer a simple question to generate a test recording, e.g. “Please can you tell me today’s date”. Following successful checks, the interview could begin. At the top of the interview, participants were reminded of their withdrawal rights, and informed that the interview could be paused for breaks as required. Interviews were conducted in accordance with the premises of IPA methodology (see Chapter 4, section 4.4); the researcher employing flexible use of the interview schedule and photographs, allowing the participant to lead the discussion in terms of content and directionality. At the close of the interview, participants were thanked for their time and issued with a copy of the ‘Thanks and Debrief Sheet’.

The procedure for interviews conducted online was slightly different. On scheduling the interview, participants who elected to be interviewed online were provided with the researcher’s Skype username, and requested to add the researcher as a ‘Skype contact’ ahead of the interview to assure connections. Those unfamiliar with Skype were directed to the help section of the Skype website for guidance (https://support.skype.com/en/skype/windows-desktop/). Participants were also sent copies of the consent form and demographic
questionnaire by email and asked to complete sign and return these to the researcher electronically no later than one day before the interview. On the day of the interview, the researcher asked participants to confirm again verbally that they had read, signed and still agreed to these terms, prior to commencing the interview itself. Additionally, visual voice participants were asked to simultaneously send electronic copies of their photographs alongside these forms, complete with the necessary titles/captions and number ordering, if required. On the day of the interview, the researcher logged-on to Skype 15 minutes before the agreed start time to test the functionality of their audio-visual equipment. Once prepared, the researcher sent the following typed message to the participant using Skype’s instant messenger function:

“Hi, I’m set-up and ready to connect. When you are ready, please select the video call function. We will then carry out a brief test call to check our settings before starting the interview. Thanks!”

During the test call, the participant was advised what would happen in the event that the Skype connection failed during the interview, i.e. the researcher would allow 15-minutes to re-establish a connection and continue with the interview. If this was not possible, the researcher would email the participant to reschedule the remainder of their interview for another point in time. Following a successful test call, the interview began. As with the in-person interviews, formalities were carried out first followed by the interview discussion, i.e. participants were asked to reconfirm their consent and reminded that the interview could be paused and/or stopped at any time. Visual voice participants were asked to have copies of their photographs in front of them, and to decide how they wanted to incorporate their images into the discussion. The aforementioned interviewing techniques employed by the researcher for in-person interviews remained consistent across both online and telephone interviews. At
the end of the interview, participants were thanked verbally and emailed a copy of the ‘Thanks and Debrief’ sheet shortly after the interview had finished.

To ensure the security of all recorded interviews, the researcher transferred files from the dictation device to a password-protected computer as soon as possible post-interview. To safeguard against loss of data, files were also backed-up to an encrypted electronic storage device. To aid transcription, the researcher made notes after each interview, detailing in particular non-verbal cues and reflective information that served to enrich the transcripts. Where possible, transcripts were generated soon after interviews were recorded.

5.6 Analytic strategy

As mentioned earlier in Chapter 4 (see 4.4), all data were analysed using IPA (Smith et al., 2009); chosen because it shares similar hermeneutic and phenomenological roots with Photovoice methodology (Brunsden & Goatcher, 2007), and for its applicability in critical health contexts, thus demonstrating suitability to the current inquiry. Participants’ photographs were analysed in conjunction with their verbal data. However, as there are no specific guidelines for analysing visual data in the context of phenomenological psychology, or IPA explicitly, the researcher developed their own strategy for incorporating the photographic data, guided by Smith and Osborn (2007). As Smith and Osborn (2007, p.67) explain, IPA is “not a prescriptive methodology it is there to be adapted by researchers”. As the men’s photographs were an integral part of the analytical procedure, all images were embedded within the transcripts, anchored to the participants narratives about their existence as men living with, or who have a history of, breast cancer; this allowing the researcher to consider them in-context as meaningful objects specific to the men’s account-giving and lifeworlds (see Papaloukas et al., 2017).
Adapting Smith and Osborn’s (2007) step-by-step procedure to fit with combining the two data formats, the researcher took the idiographic approach of beginning by looking for and connecting themes within each single case first, before continuing with the analysis between cases, and building up to more general categorisations or claims. Adopting this approach ensured that all 31 men’s accounts were treated with equal value, and that no single account was prioritised or used to orient the analysis; respecting the men’s personal autobiographies as well as their community position, consistent with the traditions of CHP and IPA, in recognising individual ‘voices’. Note, data analysis was conducted by-hand, the researcher opting not to use computer-assisted data analysis software (e.g. NVIVO), preferring to organise data manually instead; considering this a less rigid yet more thorough approach, allowing them greater freedom and flexibility in how they worked and engaged with the data, which is more in keeping with the research’s CHP framework (see Chapter 4).

Each transcript was read and re-read multiple times by the researcher who simultaneously annotated the text throughout; making comments in the right margin, referring to aspects of interest or significance in regards to what was said. Some parts of the data were richer in content – especially where text and photographs were nestled together – warranting more commentary than other portions. The researcher’s comments varied; some indicating summarisations, associations and initial interpretations, others noting linguistic choices, convergences, divergences, repetition, and paradoxes in the given account. This process was continued for the whole of the transcript.

Having read re-read and commented on the transcript in its entirety, the researcher then returned to the beginning of the transcript, revisiting the data and their comments, and using the opposite margin to note down themes they had identified. This process involved higher-level thinking and abstraction, with linkage to psychological terms and theory where
appropriate; the researcher consistently checking their sense-making and interpretations against what was said. The researcher then created a list of the themes identified within the transcript; this enabling them to look for connections between them and ascertain which themes were superordinate, which were standalone, and which could be clustered. Multiple themes were identified for each individual transcript, reflecting the richness of the data (Smith & Osborn, 2007); these were then tabulated in a coherent order, alongside information indicating where the themes could be located within the transcripts.

Theme tables were generated initially for each individual transcript, then later for the grouped themes spanning across the dataset. The tabulated information was then transferred into a schematic map to illustrate the linkage between the themes identified, leading to the discovery of three overarching masculinity-related themes which the researcher then developed into a schematic diagram (see Chapter 6, Figure 3); demonstrating how men adopt and perform different masculinities at different stages of the breast cancer episode. The writing up of the analysis in narrative form is structured according to these three overarching themes, presented and discussed across Chapters 6, 7 and 8, complimented by an overall discussion presented in Chapter 9.

5.7 Quality assurance practices

As briefly mentioned in section 5.2 (and later in sections 9.8, 9.9.1 and 9.9.2) several quality assurance practices were exercised throughout the PhD process to ensure quality and rigor of the research, both in how it was performed, and how it is presented here. First, and as previously mentioned, the inclusion of the research partner helped to ensure quality, the ‘MEB’ advising on the content and phrasing of the questions that made up the interview schedule and providing feedback on the photo-taking task; reflecting on the practicalities suitability and potential for added value when using a visual method in this research context.
Further, collaborating with the research partner fits with the participatory aspect of the research design, and reflects one of PR’s key strengths; integrating the researcher’s theoretical and methodological expertise with non-academic participants’ real-world knowledge and experiences, to aid knowledge production and potentially develop practical solutions to the research ‘problem’ (Cargo & Mercer, 2008).

Second, the researcher practiced memo-writing throughout the data collection period, making informal notes after every interview recorded; writing down initial thoughts and/or observations, reflecting on the interview process, and commenting on items of potential importance/interest which may be worthy of detailed exploration at analysis. Writing memos enabled the researcher to use the interview schedule and incorporate participants photographs with greater flexibility at interview; the notes and observations contained in these memos also contributed considerably to their reflexive account (see section 9.9). Additionally, the process aided iterative interpretation of the data, and created an important extra level of narrative: serving as an interface between the men’s accounts, the researcher’s interpretations, and wider theory (see Birks, Chapman & Francis, 2008). Keeping memos also helped the researcher to better explain their analytical choices, both at supervision meetings and when writing-up the analysis, aiding transparency of interpretations; a benchmark for good qualitative practice (Reid et al., 2005).

Third, triangulation of the two data collection methods also indicates quality and rigor, this leading to improved data analysis by affording greater depth of understanding and interpretation of the participants’ meaning-making; the integrated verbal-visual accounts offering a more comprehensive picture (Tobin & Begley, 2004) about the lived breast cancer experience for men. The rationale for and benefits of methodological triangulation in this context is discussed further in Chapters 4 and 9.
Also a form of triangulation, data analysis and the identification of themes both within and across the men’s accounts were regularly discussed with the supervisory team at supervision meetings, ensuring cross-validation of the findings; particularly checking coherence and plausibility of the researcher’s interpretations. Themes labels, tables and the maps of themes (see Appendix C) were all refined following iteration, and considerable efforts were made to ensure that themes identified were credible and added value insofar as insight; furthering understandings about men’s breast cancer experiences.

Finally, in accordance with the ‘good practice’ guidelines proposed by Elliott et al., (1999), and later Reid et al., (2005), transparency of the findings is grounded in examples from the data. All themes are supported by a comprehensive range of selected quotes and photographs taken from the men’s verbal-visual accounts. Further, the researcher (together with the first supervisor) took care to make sure that the analysis presented was inclusive and reflected the ‘voice’ of all the men who participated.

5.8 Chapter summary

This chapter has explained, in detail, how the chosen methods were applied and practiced in accordance with the research position and ethics. It has outlined sampling aspects, recruitment strategy, participant details, study materials, key ethical considerations, participation procedures, the analytic strategy and quality assurance practices. The chapter that follows forms the first of three findings-based chapters; it begins by outlining the data corpus and introducing the three superordinate themes identified accompanied by a schematic illustration, before presenting a detailed analysis and discussion of the first theme.
Chapter 6 – Data analysis – an introduction

Having outlined the methodology that informs the second half of the two-part study in Chapter 4 and explained the related method and analytic strategy in Chapter 5; Chapters 6, 7 and 8 together present an analysis and discussion of the study findings, identified following an integrated IPA analysis of the men’s verbal-visual breast cancer accounts. In the current chapter, the superordinate themes and corresponding subthemes identified within the men’s accounts are introduced. Three interrelated superordinate themes, linking to ways in which the men perform and make sense of masculinity across the breast cancer trajectory, serve as the framework for the analysis. The interrelationship between these masculinities is illustrated using a schematic representation (Figure 3, p.137); developed following refinement of the initial analysis and designed to show how the men perform and transition between masculinities as they manage, experience and make sense of the breast cancer episode, from diagnosis through to being ‘in recovery’. This representation also serves to support Connell’s (1995, p.185) earlier argument that “masculinities come into existence at particular times and places and are always subject to change”. Following an introduction to the schematic representation, and the subthemes corresponding to each of the three superordinate masculinities identified, the first masculinity – threatened and exposed – is discussed. The second – protected and asserted masculinity – is presented in Chapter 7, and the third – reconsidered and reconfigured masculinity – in Chapter 8.

Generating more than 50 hours of talk and 175 photographed images between them, the men’s experiential accounts were detailed, emotive and complex; including elements of disbelief, confusion, denigration (self and other) and self-protection, alongside self-growth and self-improvement. The findings demonstrate both shared similarities and differences in the men’s breast cancer experiences and present several paradoxes in terms of the men’s
responses to the illness, versus what they said men need and/or want for an improved breast cancer experience. The men’s visual representations were diverse; the data comprising photographs of the men’s embodied selves, nature, scenery and places, medication and clinical settings, and inanimate objects which the men related to their breast cancer experiences in their own idiosyncratic ways. Some photographs were visually obvious in terms of their linkage with the breast cancer episode, requiring minimal explanation as to what they represent and the reasons for their inclusion. Others required phenomenologically thick description (Smith, 1996) and interpretive explanation by the men to establish their true meaning, and the feelings and memories associated with the visuals; affording deeper hermeneutic discussions and experiential understandings accordingly (Papaloukas et al., 2017). As expected, integrating the men’s verbal and visual breast cancer accounts enabled the men to comprehensively ‘give voice’, and to depict, with greater clarity, experiential instances of their lives which, for them, are central to the male breast cancer experience. The benefits and challenges of the integrated approach and the visual voice method are discussed in Chapter 9 – 9.5 (see also Papaloukas et al., 2017).

Extensive data analysis of the integrated data forms yielded multiple themes corresponding to the men’s constructions of both breast cancer and masculinity in line with their illness experiences. Twelve dominant themes comprising more than 60 subthemes between them were identified across the men’s accounts, illuminating the psychosocial, psychosexual and socio-political difficulties encountered by men diagnosed with breast cancer, and how the gendering of breast cancer affects men at every stage of the illness episode. A schematic map including all 12 themes and subthemes as they were originally identified was generated to refine and narrow down the analysis (see Appendix C); and from further reducing the multitudinous number of themes, three connected superordinate masculinity themes were then
identified. The men’s accounts of their breast cancer experiences demonstrate how the men express and come to conceptualise masculinity across the illness trajectory and move between the three masculinities identified as they manage and make sense of their breast cancer diagnosis and the ensuing repercussions, which for some remain ongoing into recovery (Figure 3).

\textit{Figure 3.} A schematic representation illustrating how men transition between the three superordinate masculinities identified

\textit{Threatened and exposed masculinity} pertains to how the men, both directly and indirectly, discuss and illustrate the ways in which receiving a breast cancer diagnosis serves to threaten their male identity. This is typically the first masculinity men perform in relation to breast cancer, exhibited in the early stages of illness when the men realise their vulnerability; not only in terms of the potential threats posed to their health and wellbeing, but also to their social standings and male embodiment, as they become marginalised from hegemonic positions (Connell, 1995).
Protected and asserted masculinity demonstrates the men’s desire to maintain hegemonic or leading male roles and positions in their lives, and to preserve a high social status despite the breast cancer diagnosis (Courtenay, 2000). This expression of masculinity typically comes after the men recognise their threatened-exposed positioning as men diagnosed with an illness that is generally afforded a female status, relating to control and power, but also exposes the tentacles of breast cancer and its wider impacts; for example, the effects it has on the men’s significant others and how this in turn impinges on the men’s sense of self.

Reconsidered and reconfigured masculinity exemplifies the men’s changing perspectives on ‘being male’, health and illness – especially breast cancer – and life more generally following their breast cancer experiences. Reflecting on the illness episode, and their changed selves accordingly – physically and psychologically – the men articulate positives in the breast cancer experience, including benefit-finding (Stanton et al., 2002) and self-development, and exhibit evidence of successfully re-thinking their personal biographies (Bury, 1982) and identities as men recovering from breast cancer.

From pre-formal diagnosis to receiving the confirmed breast cancer diagnosis and undergoing treatment, the men appear to move back and forth – almost simultaneously – between the first two masculinities, before transitioning onto a reconsidered and reconfigured masculinity; this is more characteristic of being in the latter stages of treatment, as they advance towards being ‘in recovery’ from breast cancer. Note, these masculinities are not mutually exclusive of one another, rather they are interconnected with some overlapping evident between them as the men, or at least those whom reach the recovery stages, transition from one masculinity to the next over time, across the illness trajectory.

Though this representation is typical of the majority of the men who contributed data for the study, it is important to acknowledge that this is not applicable to all of the men; for instance,
for the men whose breast cancer had metastasized, though they progressed onto a reconsidered and reconfigured masculinity, they also exhibited evidence of regressing back towards a threatened and exposed masculinity on recognising the incurability of their breast cancer and their deteriorating health and social statuses. Of the 31 men interviewed, only one man did not advance beyond the first two masculinities; this coinciding with his extreme negative psycho-emotional response to developing breast cancer, which no other participant articulated to the same extent.

Following refinement of the analysis and identification of the three superordinate masculinities, 14 subthemes remained; four/five subthemes corresponding to each masculinity. An overview of the masculinity themes and related subthemes is presented in Table 8.

**Table 8. The Three Superordinate Masculinities and Associative Subtheme Headings**

<table>
<thead>
<tr>
<th>Threatened and exposed masculinity</th>
<th>Protected and asserted masculinity</th>
<th>Reconsidered and reconfigured masculinity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marginalisation from multiple sources</td>
<td>‘Being’ male: stereotypically reasoning why he developed breast cancer</td>
<td>Life beyond breast cancer</td>
</tr>
<tr>
<td>Clinically vulnerable: mishaps, challenges and concerns</td>
<td>Maintaining normality</td>
<td>Embracing new opportunities and life experiences</td>
</tr>
<tr>
<td>Physical reminders: the embodied breast cancer experience as a man</td>
<td>Downward comparisons: breast cancer as worse for others</td>
<td>Renewed identity: becoming a changed/better man</td>
</tr>
<tr>
<td>Breast cancer as a constant: lasting impressions of the illness episode</td>
<td>Resisting formal support while recognising its worth</td>
<td>Engaging with breast cancer activism and advocacy</td>
</tr>
<tr>
<td></td>
<td>Proving male credentials</td>
<td>New and improved relationships following the breast cancer episode</td>
</tr>
</tbody>
</table>
The refined subthemes and their linkage to the three masculinities identified serve to further explain the superordinate themes and illustrate how the men perform and conceptualise masculinity in making sense of their breast cancer diagnoses, as they navigate their way through the complexities of the illness experience.

Together, the findings serve to enhance how men’s experiences with breast cancer are understood; how they make sense of and cope with not only the breast cancer challenge itself, but also the relative issues MEBs face, as will now be explored across the present and following two chapters.

6.1 Analysis – Superordinate Theme One: Threatened and exposed masculinity

As Charmaz (1995, p.268) noted in her writings on identity dilemmas in chronically ill men: “illness can reduce a man’s status in masculine hierarchies, shift his power relations, and raise his self-doubts about masculinity”. Based on the findings of this research, and indeed the small body of psychosocial research that goes before it (see Chapter 3, and Quincey et al., 2016), this appears to be true of men diagnosed with breast cancer; since these men, who are marginalised by dominant male norms and ideals, have a subordinate relationship to hegemonic masculinity (Connell, 1995), which can lead to male identity crisis. Though little is known to date about men’s sense of embodiment and masculinity when diagnosed with breast cancer, research into other reproductive male cancers (e.g. prostate cancer, Chapple & Ziebland, 2002; penile cancer, Branney et al., 2011) has shown that the burden of cancer in men impinges on their self-identity and sense of masculinity, and that male image is adversely affected by illness, especially if this means having to seek help and become dependent on others; practices which are uncharacteristically male (Chapple & Ziebland, 2002) yet
commonplace in the context of cancer. Hence the men’s performance of a threatened and exposed masculinity when being tested and treated for breast cancer; an illness which for most of the men presented as an unexpected life course disruption (Bury, 1982), and an unfathomable illness reality for them as men, given breast cancer’s stereotypical female identity (Sulik, 2011). In order for men to conform with dominant masculine norms and ideals, they must adhere to cultural definitions of male beliefs and behaviours, which involves, in part, rejecting what is feminine (Courtenay, 2000); hence the perceived threat and chaos that ensues in men when they develop breast cancer.

Typically shown in the earliest stages of the breast cancer episode, including pre-diagnosis, the threatened and exposed masculinity presents as the men become aware of their ill-health and begin to cognitively process the potential threat posed; not only to their health and mortality, but also to their male identity, given breast cancer’s incongruence with cultural constructions and expressions of masculinity, e.g. strength and imperviousness (Clare, 2001). As the men progress from pre-diagnosis to formal diagnosis and commence treatment, they become increasingly aware of the personal meanings attached to their masculinity, especially their embodied masculinity, and breast cancer’s propensity to compromise this; since the illness and methods used to treat it (e.g. mastectomy) typically cause changes to bodily appearance. Thus, almost all of the men articulated the advent of breast cancer to induce feelings of vulnerability and emasculation, exemplifying why and how in multiple ways, including; being marginalised from socially dominant or leading male positions, experiencing reduced autonomy and power struggles, and challenging long-established and taken-for-granted assumptions about their male self and embodiment.

Many of the participants reported losing male roles and/or male abilities subsequent to developing breast cancer, ranging from no longer being able to fulfil work and family roles, to
the inability to play sports and perform sexually; all of which are common side-effects of cancer treatments, but are nonconforming with conventional masculinity. Thus, and in accordance with Threatened Masculinity Theory (see Mishkind et al., 1986), the men typically viewed these losses as a personal failure, irrespective of the fact that most were beyond their personal control; their inability to perform masculinity post-diagnosis, as it is traditionally prescribed, leading to psycho-emotional conflict and a confused sense of self.

Regarding power, men exercise varying degrees of power; not only over women, but also among themselves (Courtenay, 2000). As the men’s breast cancer accounts demonstrate, not all men are alike or perceived as being equal, therefore as Connell (1995) recognised, the concept of a single masculinity is reductive, as thoughts about what constitutes ‘being’ male and male hierarchies are ever-developing, leading to the evolution of multiple masculinities and male identities. Dominant masculinities (and indeed femininities) subordinate marginalised masculinities and do so through practices such as exclusion intimidation and exploitation (Connell, 1995, p.37), all of which men with breast cancer seemingly experience, according to the men’s accounts; further indicating that breast cancer in men is a marginalised malignancy (see Chapter 3) and that affected males personify marginalised masculinity. This again illustrating their threatened-exposed position.

As chronic illnesses can threaten masculine identities and cause identity dilemmas, equally these dilemmas themselves can become chronic (Charmaz, 1995); especially body image dilemmas, which, as the men’s accounts show, can be recurrent in the context of breast cancer. As male body image research has shown (e.g. Pope, Phillips & Olivardia, 2000), body image issues can hinder men’s (and also women’s) social and occupational functioning in a variety of ways; for instance, causing men to change work behaviours, avoid sexual contact, and wear additional or loose-fitting clothing to hide their bodies due to feelings of shame and
dissatisfaction – both of which have been found to negatively correlate with feelings of masculinity (McCreary, Saucier & Courtenay, 2005). Many of these same practices (among others) were also reported in the men’s breast cancer accounts, with body dissatisfaction post-treatment also serving to exemplify the threatened-exposed masculinity identified.

Four associated subthemes serve to further illustrate the concept of a threatened and exposed masculinity and are tabled below. Note, some of the photographs used to represent these and later subthemes include identifiable materials; these will be anonymised when the research is more widely disseminated.

Table 9. Subthemes for Superordinate Theme One

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6.2 Marginalisation from multiple sources: “We’re under the radar…that upsets me” (Andy, line 48)

This first subtheme explores when, where and how the men experienced marginalisation – both enacted and felt – relative to experiencing breast cancer; how they make sense of being/feeling marginalised in different contexts by different persons practices and systems, and how this influenced their responses to illness accordingly.

All of the men interviewed articulated experiencing marginalisation in some form or another relative to their breast cancer diagnosis; this presenting in different guises, with the men’s
accounts exemplifying evidence of both self- and other-stigma, the latter coming from a range of sources, including female patient-survivors and health professionals, thus supporting earlier findings (see Chapter 3). Self-stigma was frequently articulated across the data, the men unconsciously describing the variety of ways in which they marginalised themselves – actively or otherwise – through their behavioural practices, beliefs about and attitudes towards both breast cancer and masculinity. Examples of self-marginalisation included rejecting formal support (see Chapter 7, 7.4) and dismissing informational materials, being purposefully passive in clinical decision-making, and declining to use patient services they perceived as intended for women.

The men’s linguistic choices in giving voice to their breast cancer experiences also presented as self-marginalising, with them frequently using derogatory terms when describing breast cancer in men, including locutions such as; ‘strange’ ‘unusual’ ‘alien’ ‘odd’ and ‘sideshow’. Interestingly, the men seemed to deploy this as a way of coping, with some admitting to implementing a policy of ‘getting in first’, in an attempt to reduce the threat posed to their male identity, like Jason:

“They knew me as the freak hah cos that’s what I called me self when I went to see ‘em”

(Jason, lines 87-88)

On the one hand, Jason describing himself as “the freak” implies nonchalance on his part at being perceived as atypical, and outwardly projects that he is impervious to othering; yet, on the other, it could be argued that he self-subordinates from the leading male position, marginalising himself and other men with breast cancer by using such derogatory phrasing in distinguishing himself from the male norm.
Almost all of the men referred to breast cancer as being a female illness, despite having experienced the diagnosis first-hand themselves as men; incorrectly positioning it as a gendered condition, as Graham did:

“*I thought of all the cancers to get I had to get a bloody women’s cancer*”

(Graham, lines 36-37)

Graham’s deprecating comment here reflects his indignation at developing a cancer that is primarily understood to affect women and how he perceives this to affront his male identity; this is representative of the men’s general ignorance about breast cancer, and further demonstrates how men themselves perpetuate common misconceptions about the illness.

The unknown and unwonted status of breast cancer in men seemingly had a profound influence on the way the men viewed the illness and themselves as MEBs, as this excerpt from Roy’s account demonstrates:
“this is how I feel about me and my colleagues let’s say (.) we are mythical beasts we do not exist (.) me and other men who ‘ave breast cancer we are pink unicorns... mythical beasts... people don’t believe in us... the reaction to I’ve had breast cancer WHHHAAAAAATTTTTTT YOU ooh y’know it’s the same reaction t’ well if somebody said I’ve just seen a unicorn people won’t believe you they’d look at you like WHAT NAHHHHHHHHH”

(Roy, lines 1453/1454, 1455-1475)

Roy believes that men developing breast cancer is socially conceived almost as something fantastical, even an impossibility to some; a view he bases on peoples’ reactions of disbelief to his own diagnosis, hence likening himself and his male “colleagues” to “pink unicorns”, i.e. nonsensical “mythical” beings that are remote from reality, defying social expectations and beliefs. In articulating the psychological impact that people failing to recognise the illness has on men, Roy commented: “you don’t exist and obviously that knocks you down ‘you’re a zero° and that’s hard” (line 1667-1668); this illustrating how men with breast cancer perceive themselves as marginal men (Park, 1928), unseated from the hegemonic male position (Connell, 1995) and unable to fully assimilate with typical male or breast cancer patient identities. Relatedly, Roy also explained how the pink hue of the image is purposeful here, reflecting his feeling that men with breast cancer are positioned and operate at the periphery
of the breast cancer community which is frequently represented by the colour pink, indicative of its linkage with hegemonic femininity (Sulik, 2011): “if it’s anything to do with breast cancer it’s gotta be pink... that’s the rule” (lines 1488, 1490).

Several of the men commented on pink representations of breast cancer, the association of pink with women and femininity, and how this serves to marginalise male patient-survivors, threatening their masculinities in a variety of ways, including; engendering feelings of exclusion and isolation among affected males, e.g.: “I have a pink t-shirt that says real men wear pink but that’s designed for male supporters, husbands, not men with breast cancer” (Peter, line 1178-1179); making it difficult for men to find information among the pinkness and to fully engage with support services, including those online.: “I could tell you everything about women wearing pink...but men... that page...you’ve gotta hunt for it” (Robert, line 1062-1065); and hampering raising men’s awareness: “before I would never ‘ve thought that men get it it’s all pink” (Neil, line 36). Although the pink culture surrounding breast cancer was generally articulated by the men as unhelpful and negative against men, interestingly, most were keen to demonstrate embracing the related pinkification and feminisation; taking it as given, typically perceiving pink symbolism as a fixed social representation that has cemented over time and is unlikely to change. Though the men’s expressed readiness to go along with the pinkification of breast cancer could be interpreted as an act of self-marginalisation, insofar as perpetuation through passivity and resignation, it could also be argued that their need for belongingness perhaps outweighed their desire for parity. That said, some men did voice suggestions for possible ways to rethink pink symbolism, particularly the pink ribbon, in order to facilitate greater inclusivity and reduce men’s perceptions of threat and marginalisation; for example, apportioning the symbolic ribbon according to the female-to-male ratio of breast cancer diagnoses:
“three quarters pink a quarter blue to reflect the sorta levels the numbers of men y’know there’s got t’ be some way of highlighting this”

(Glenn, lines 1053-1055)

“I get so fed up of seeing pink everywhere... even if it just had a blue dot just something...let men get involved”

(Neil, line 865, 1067-1068, 1189)

Many men expressed their annoyance at the invisibility of men within breast cancer culture and the non-inclusivity of the pink ribbon but were conscious about detracting from women in gaining recognition for men; hence, both men explicitly acknowledge the disproportionate number of male diagnoses, this reflecting their desire for true breast cancer equality, rather than merely elevating affected men.

Echoing Roy’s sentiments that breast cancer in men is akin to make-believe constructs, Jonathon similarly articulated his breast cancer experience as a “great fairy-tale” in the sense that although the illness was and remains a part of his reality, to him, it did not seem real; rather, he described it as “almost running parallel to life” (line 1645), which continues regardless, before increasingly becoming a part of it. Jonathon chose to visually represent this by taking a photograph of a painting he composed whilst undergoing treatment for his breast cancer; the dark and pernicious depiction intended to reflect the fictitious feeling, negativity and anger associated with the ambiguous diagnosis, temporary recovery and uncertain future he now faces with his breast cancer metastasising:
“the whole of what I was dealing with for many reasons was both reality but also a fairy-tale... what’s going on around you it’s all a great fairy-tale you never know what the truth is... so I think of breast cancer as a great fairy tale in some ways... I don’t like fairy-tales very much I think they’re malevolent things in many ways they’re not nice things they can be very unpleasant and cancer can be very unpleasant”

(Jonathon, lines 1615-1657)

Describing breast cancer as a “malevolent” and “unpleasant” falsehood, and later as something which “invades and overlays everything” (lines 1624-1625), Jonathon discussed feeling threatened by his diagnosis, articulating himself as under attack from breast cancer; viewing the illness as something beyond and outside of him that he has to embrace to regain order and control in his life post-diagnosis. Further relating to this fairy-tale concept, referring to his artwork, Jonathon likens breast cancer to a fairy-tale-villain that is “out to do harm” (line 1643) and needs to be defeated; indicating its perceived overpowering and threatening
presence, and feeling marginalised and disempowered following diagnosis, though not yet overcome by the imposing “dark figure” (line 1616), i.e. the illness.

In addition to self-marginalisation and feeling marginalised by pink representations and the perceived illusoriness of breast cancer in men, several men also discussed experiencing marginalisation from members of the breast cancer community, especially women. Manifesting in both explicit and discreet forms, the men across their accounts described numerous occasions where women’s attitudes and/or behaviours towards them presented as hostile and marginalising. For instance, Peter recounted how he experienced hostility from female patient-survivors when volunteering at a breast cancer fundraising event:

“I have to say I find that women don’t really want men there... I was the only man and they really looked at me like I was some kind of alien creature yeah some seemed to find it very difficult to talk to me I went along I got a cap with a pink ribbon and survivor on it cos I mean I am y’know err so I decided I wouldn’t do it again because I really didn’t feel welcomed and y’know men do come up against this”

(Peter, lines 822-823,1112-1117)

The othering that Peter encountered suggests that the women viewed him as being intrinsically different from themselves, and possibly invading a space of sisterhood, and either could or would not recognise his shared credentials as a breast cancer ‘survivor’; this Peter attributed to his male identity and its incongruence with the typical female identity of breast cancer patient-survivors. Feeling unwelcomed and alienated by this experience, Peter expressed his disinclination to participate in future events; put-off by the possibility of experiencing further marginalisation, thus missing out on opportunities to engage with the breast cancer community.
A number of the men also reported being marginalised by women in patient-dedicated spaces, causing them to feel ill-at-ease and self-conscious when present in such settings:

“it was a bit strange sort of sitting in the waiting room and being the only unaccompanied male (.) you always get that sort of ‘what’s he doing here’… so you sit there looking awkward”

(Paul, lines 917-919, 921)

Paul, among others, articulated feeling out-of-place in patient waiting areas which were typically heavily populated with female patients; his male presence often attracting undue attention from these women, usually discerning “looks” or “sideways glances” (line 823). Several of the men discussed feeling exposed in such settings and the awkwardness of picking up on implicit cues from women who appeared to doubt their patient credentials as men: “it’s ranged from outright sympathy to bafflement…some people have been baffled by the fact that I’m a bloke” (lines 185-187).

In discussing women’s reactions to their illness, the men rarely portrayed female patient-survivors as being relatively indifferent or opinionless, rather they positioned them at the extremes; either positive and inclusive, or negative and hostile towards male counterparts. Eammon explained his experience of going from one extreme to the other regarding women’s reactions to his involvement with breast cancer advocacy, from encouraging him to participate in support groups: “I was made very welcome at all the sort of breast cancer groups because it was a great novelty to have a man” (lines 2311-2313); to later accusing him of “taking the limelight” for repeatedly serving as the male representative at local breast cancer events, due to the limited number of men available: “some o’ the women didn’t like it because y’know oh he’s taking over so that’s why I started to back off a bit” (lines 2350-
Eammon discussed how subsequent to experiencing this indirect hostility, he actively reduced engaging with breast cancer activism and advocacy, uncomfortable at the thought that his male presence undermined affected women – inadvertently or otherwise – since that was never his intention, rather: “just achieving balance” (line 2362). Further, in addition to unfriendliness from affected females, Eammon also reported experiencing hostility and marginalisation from breast cancer charity personnel:

“I noticed that suddenly I wasn’t invited to a lot of major events that the charities were running and that was because if I was there the press inevitably homed in on me... you see the politics o’ these things”

(Eammon, lines 423-426, 481)

Eammon explained how being one of only two known men with breast cancer in his region, local charities and media regularly sought his input, which despite initially having mutual benefit, over time came to disadvantage him. Believing that he was strategically excluded from events, given the propensity of his male presence to divert attentions away from the intended focus, i.e. the event organisers, Eammon considered this marginalisation was an example of breast cancer politics in action, further indicating that breast cancer charities may not be wholly philanthropic, as has previously been mooted (Sulik, 2011).

As well as experiencing hostility in physical spaces, some men encountered antipathy from women in virtual environments too, reporting examples of antagonism in a number of online settings exclusively used by members of the breast cancer community, including blogs and social media groups. For instance, Tom was challenged by a woman about a photograph he posted on his blog which he used to visually demonstrate the embodiment of his breast cancer; his intention to raise awareness and inform others:
Undeterred by her questioning his decision to include the visual representation, the image remains a part of Tom’s blog, reflecting his belief that to shy away from the physical reality of breast cancer in men is to subordinate it, and moreover, to disservice future men affected by the illness.

Similarly, Roy experienced antipathy from members of an online breast cancer community when he uploaded a photograph of his post-breast cancer body to a dedicated Facebook page, intending to inform others about the after-effects of his radiation treatment:
Roy was issued with the ultimatum of removing the image from Facebook or having his account permanently disabled, preventing any further interactions between him and other site users; potentially denying him opportunities for social support and marginalising him further from the wider breast cancer community. Roy expressed his reluctance to remove the photograph calling the request “ludicrous” and appeared visibly frustrated in the interview that the image could no longer feature on his Facebook profile, despite being representative of his post-breast cancer male embodiment, simply he said because others “can’t face it” (line 1446) “looking at the reality” (line 1443). Although neither Tom nor Roy could categorically determine whether the hostility they experienced was gender-based, both maintained that equivalent imagery representing breast cancer in women persisted to present in both on- and off-line spaces, suggesting there is perhaps greater social acceptance of female breast cancer imagery, further indicating the marginal position of men with breast cancer.
6.3 Clinically vulnerable – mishaps, challenges and concerns: “It was a year and a half before I was diagnosed” (Darren, line 69)

This subtheme reflects the men feeling disadvantaged by clinical breast cancer practices and patient support services, and how their marginalised position within clinical contexts served potentially to threaten not only their health, but their sense of self, and male and breast cancer patient identities.

In discussing the marginalisation of men with breast cancer, the men specifically articulated feeling disadvantaged by clinical breast cancer practices and demonstrated in a variety of ways how their marginal position within clinical contexts served to threaten their diagnosis, treatment and recovery, as well as their male and breast cancer patient identities. Despite the majority stating that they were happy overall with the clinical care and treatment they received, many of the men shared stories where clinical encounters had left them feeling vulnerable and exposed; indicating a sense of insecurity – physical and emotional – and emasculation accordingly.

The men consistently reported how they were often assumed to be female when attending and/or trying to arrange their clinical appointments, and were frequently addressed using female titles in clinical settings, e.g. Mrs; clinicians unintentionally yet repeatedly showing disregard for their male identity, caused men discomfort:
“they naturally assume even though they’re professionals it’s a lady not a man until they look at the notes”

(Geoff, lines 837-839)

“y’know you’re not very happy about it... I were sitting in the waiting room with me wife and this registrar stuck his head out the door and shouted MRS X(.) we went in and I said er it’s not Mrs and me wife I think spoke a bit more strongly than that”

(Ken, lines 84, 138-141)

Geoff’s comment “even though they’re professionals” implies that he expected clinical personnel to show greater awareness of breast cancer in men than they perhaps did, highlighting discrepancies between men’s clinical expectations and reality; this having the propensity to leave men feeling vulnerable, threatened by the perceived lack of regard for the illness in men. Ken explicitly correcting the registrar illustrates his displeasure at the oversight, and also the perceived threat that he, as a man, associates with being thought of in female terms, perhaps viewing this as an affront to his masculinity; his experience, nevertheless, further demonstrating the inherent gendering of breast cancer in clinical settings, as research has previously discussed (Quincey et al., 2016).

Not only did the men’s accounts show clinicians to commonly overlook their male patient identity, in some instances, they overlooked their patient identity altogether; presuming men in clinical settings were there as supporters of female patients rather than service users, and consequently causing them to feel out-of-place, as Graham explained:

“...I felt quite self-conscious at the clinic... people looking like what the hell are you doing here? ...someone actually asked me “so which one’s your wife?””

(Graham, lines 424-430)
Generally, the men agreed that “the medical profession isn’t geared up to protect male patients” (Jason, line 66) in the way it does women with breast cancer, and based on their experiences, most considered that men were treated differently to women in clinical settings. For instance, Jason described how he was made to walk an unorthodox route to his consultant’s office to avoid him from potentially coming into contact with female patients, in case his male presence caused them further distress:

“The instead o’ taking me directly to the consultant’s room they ‘ad t’ take me right round the different route o’ corridors just in case a door was open and there was woman in there or I came across some women who were upset after getting news or treatment”

(Jason, lines 74-77)

This instantiates Jason’s prior comment that clinical practices fail to protect men, and further that they prioritise the protection of women to the extent that men’s needs become subordinated; causing men to feel inferior to women, and perhaps inciting men to engage in self-marginalisation as earlier mentioned.

Generally, the men’s accounts implied that clinicians typically show over-concern for women and not enough for men; a further example of which was provided by Ken, whose consultant asked him to self-censor his pained reaction to a needle biopsy, so as not to disconcert the women waiting to undergo the same procedure:

“He stuck a biopsy needle straight in my nipple and I screamed cos it was painful incredibly painful and er the sympathy I got from the consultant at the time was er he just told me to shut up cos I’d upset the women outside”

(Ken, lines 142-146)
Jason and Ken’s experiences both serve to evidence the claim that male breast cancer patients are marginalised within clinical settings, and that clinicians actively marginalise men through some of their practices; influenced by gendered understandings about the illness, despite its non-gendered reality. A number of the men believed that they were treated differently to how a woman would have been managed; like Neil, who was formally misdiagnosed twice, before being tested for breast cancer:

“it was 3 years beforehand when I first found the lump and went to the doctor... because I’m male... if I’d ‘ave been female they’d have taken a biopsy from the first visit if not definitely the second if it’d got bigger no doubt about it... I can’t get my head round how different I was treated to if I was a woman cos I know damn well they would’ve got a biopsy they’re so big on it an’ I can’t understand why they’d treat men different”

(Neil, lines 201, 214, 216-217, 671-674)

Neil firmly believed that the clinical decision for him not to undergo a biopsy test was based solely upon his doctor’s own gendered assumptions about breast cancer, attributing the negligent practice to gender discrimination, and further highlighting the vulnerability of men in the pre-diagnosis stage. Though he was never personally misdiagnosed, Bill shared Neil’s belief that clinicians respond differently to men presenting with potential signs and symptoms of breast cancer than they do women, believing that there is perhaps an overreliance on breast cancer statistics, causing men to be overlooked:
“When I first went to the GP the problem was I was being diagnosed by statistics... in fact not considering it because of statistics...
I think it’s important that men don’t get ignored because of statistics... it may have been that one doctor but it’s an indication of something that can happen”

Bill, lines (1252-1253, 1262, 1270-1271, 1279-1280)

A number of the men discussed having grave concerns about being managed according to breast cancer statistics given that they are typically based on female data, and openly admitted that they were threatened by the ambiguity surrounding best treatment and care practices for men. Further, the men also articulated their frustrations at the lack of male-specific data made available to them, and felt clinicians providing them with female statistics affronted their masculinity, viewing this as inappropriate and insensitive to their male needs, as Michael explained:
“I was given a piece of paper about erm life expectancy for people with breast cancer but it wasn’t people it was women... what good is this to me? I said (.) so you’ve got no facts and figures on men an’ how they’ve responded to breast cancer or how long they live or (.) and he didn’t know what to say (.) I couldn’t believe that I’d been given statistics that related to women and not men.”

(Michael, lines 50-51, 54-59)

Coupled with feeling angry and ill-informed at the lack of available male information, this also served to remind Michael – and others – how few men are formally diagnosed with breast cancer, further highlighting their rare and exposed position. As Charles said: “there is a feeling when you get diagnosed that you are on your own” (line 647). This indicating the sense of isolation and not-belonging that men often experience in line with a breast cancer diagnosis; feelings which are seemingly brought to the fore in clinical settings, leading men to deduce that breast cancer is “not designed for men” (Paul, line 388).

Concerned that they were treated according to best practices for women not men despite male breast cancer’s incongruence with the disease in women (Fentiman, 2016), many also articulated feeling clinically vulnerable with regard to clinicians making treatment decisions for them, yet paradoxically, less personal autonomy presented as preferable, the majority reasoning: “they’re the professionals they know what to do” (Jason, line, 1288). As part of their treatment, many of the men were prescribed Tamoxifen; an antineoplastic drug used to treat and prevent the growth and spread of breast cancer cells. Though the efficacy of the drug is well-researched for use with women (e.g. Nazarali & Narod, 2014), knowledge about Tamoxifen use in men remains relatively limited; hence men who were prescribed this treatment typically expressed concern over its appropriateness.
Tamoxifen was a common talking point across the men’s accounts, with particular reference made to the threat of both known and unknown side-effects of the drug. When discussing Tamoxifen and its side-effects, the men used words such as ‘enemy’, ‘evil’ and ‘bugbear’, indicating its association with perceived threat and unpleasantness or as Tom referred to it “Tamoximoron” – a play on words for oxymoron, reflecting his paradoxical thinking:

“It’s a weird thing cos I hate it (.) but it could be keeping me alive (.) a double-edged sword... it’s affected me so badly (.) stop takin’ it who knows what might happen... might die... don’t know what it’s doin’ to ya what it’s goin’a do if you stop takin’ it (.) is it my friend is it my enemy I don’t know”

(Tom, lines 1481-1500)

Tom’s illustrates his turmoil at continuing to take Tamoxifen and enduring its unpleasant side-effects or ceasing the medication and risking the chance of breast cancer recurrence. Describing Tamoxifen as “a double-edged sword”, Tom reflects his uncertainty about whether it is doing him more good than harm; hence querying if it is his friend or foe, further indicating the perceived threat associated with the medication.
Using equally paradoxical phrasing, Peter said “I’m dying to get rid of it” (line 1449) reflecting his desire to stop taking Tamoxifen and rid himself of the unwanted side-effects plaguing his self-esteem; including weight gain and loss of libido, which he perceives to affront his male image. Peter also expressed how he hated the regimen of taking Tamoxifen on a daily basis, suggesting he felt ruled by the medication, and in turn, disempowered by adhering to the treatment.

Not only did the related side-effects undermine the men’s sense of masculinity and cause them to feel psychologically vulnerable, so too did the reactions of some health professionals to the men taking Tamoxifen. For example, several men reported being challenged by pharmacists when collecting their Tamoxifen prescriptions, like Ewan:
“the senior chemist said “oh hang on” he came over to me “why you having Tamoxifen?” I said well I’ve just ‘ad breast cancer “ahhhhhh right okay no problem” he said “you’re the first ever” ...he’d never come across that”

(Ewan, lines 727-733)

In highlighting that Ewan was the first man he had ever dispensed Tamoxifen to, the pharmacist draws attention to the uncommonness of breast cancer in men, potentially serving to threaten Ewan’s masculinity by implying that he is one-of-a-kind, or a special case. Equally, this reaction also segregates Ewan from the archetypal breast cancer patient, fostering feelings of not-belonging, and incongruence between identifying both as a man and someone with breast cancer.

The men recounted several instances like this where their breast cancer patient credentials were called into question by professionals, articulating their expressed doubts to have a profound effect on their masculinity and coping; as Tom said: “I thought it’s bad enough as it is without you questioning it” (lines 1532-1533). This comment illustrating the difficulty men themselves experience in making-sense of the ambiguity surrounding the illness and treatment methods in men, without dealing with others projections too; especially health professionals, whom they expect to be more understanding.

Another example of being made to feel uneasy by a health professional was provided by Colin, whom, because of his male gender, was prevented from participating in a clinical trial researching Tamoxifen use in breast cancer patients:
“I picked up this piece of paper which said somebody was doing some research into Tamoxifen... I rang up left a message and this woman rang back “well thank you for ringing but you’re no use” or words to that effect I said why “you’re a MAN” I said well you want people with breast cancer don’t you that’s what it said “OH this is for WOMEN”... I thought very negatively about that I was trying to help... I was pretty choked off actually”

(Colin, lines 540-571, 577, 588)

Though there may indeed have been legitimate clinical reasons as to why Colin’s offer of participation was rejected, without such explanation, he was left feeling confused and upset about being excluded from the trial, viewing this merely as a case of gender discrimination. Feeling exposed by the experience, Colin admitted that the professional’s response put him off engaging with future clinical trials: “if that’s the entrenched attitude forget it” (line 594), potentially denying him opportunities.

As well as expressing concerns about undertaking certain breast cancer treatments, some of the men also shared their apprehensions about treatment coming to an end. Reasons included breast cancer recurrence fears and doubts about making a full recovery, to concerns over cutting ties with clinicians and support being withdrawn, as Andy discussed:

“now that I’m coming to the end of m’ treatment I’m worried I won’t have a shoulder to cry on kinda thing or the support... it’s something that’s worrying me”

(Andy, lines 453-455, 457)

Andy’s concerns possibly stem from there being no protocoled pathway of care for men recovering from breast cancer; this presenting as a concern for many of the men, who from
their own experiences, noted a number of differences in aftercare provisions for men and women, like Ed:

“they said to me you’re gonna ‘ave mammograms every two years but b’cos I wasn’t a female over a certain age I wasn’t recalled automatically I ‘ad t’ remember to make the appointment”

(Ed, lines 536-538)

Similarly, Bill recalled having to remind his consultant that his Tamoxifen medication was due to be reviewed after realising this had been overlooked:

“they said five years and in fact I had to tell them when the five years was up”

(Bill, line 373)

Both Ed and Bill’s experiences serve to indicate that current breast cancer patient management systems are ill-equipped to cater to men’s needs, potentially posing a real and serious threat to men’s health, as well as demonstrating men to be at the periphery of optimal care.

In considering gender differences in aftercare provisions, the men spoke at length about breast reconstruction; specifically, not being afforded the same reconstruction opportunities as women. The men’s views on and knowledge about breast reconstruction options varied considerably; though some were fully informed about reconstruction possibilities by their clinicians, in some cases: “it was never discussed” (Jason, lines 447-448) (see Misery & Talagas, 2017). Of the men who were not offered reconstruction, most considered that their male gender had influenced their consultants’ decision to omit this option from their care plan. In some instances, this belief was confirmed by clinicians’ responses to the men’s enquiries about breast reconstruction:
“I asked about it but it was laughed off... well it was that sort of attitude... her attitude was wellll y’know erm why would you want reconstruction surgery(.)”

(Derek, line 473, 475, 494-495)

That many were never made aware of the reconstruction options available for men, and that some men’s enquiries were brushed-off, suggests men’s appearance-related concerns continue to be overlooked by clinicians, and indicates further bias against men in breast cancer practices. Some men were however warned off reconstruction for seemingly legitimate medical reasons, though like Darren, these men were sceptical about the real rationale behind this advice; questioning whether they were being strategically disadvantaged by their healthcare provider:

“they told me I could have had something done but because of the size of my scar they reckoned it would have infected it and made it worse...I don’t know if they just said that though I’ save money”

(Darren, lines 199-200, 204).

Although none of the men had undergone reconstructive surgery, several had given the procedure serious thought; most thinking about it post-mastectomy after seeing the reality of their changed bodies, but some, like Jim, gave it due consideration pre-mastectomy:
“the day before the operation I thought I am going be operated on tomorrow and I won’t look like this again let’s take a picture (.) I also thought if I was going to have reconstruction it would be useful to have a picture to give some guidance as to what they are reconstructing”

(Jim, lines 763-766)

Jim’s decision to photograph his body pre-mastectomy demonstrates the concern he had about his bodily appearance changing, and the personal meaning attached to his physical appearance; acutely aware that he would never look the same again, and not wanting to forget his former self-image. It also implies that whilst pro-reconstruction, he had reservations about how a reconstructed breast might look (as do many women, see Lee, Hultman & Sepucha, 2010), threatened by the potential for it to worsen rather than improve his post-mastectomy appearance. This thinking was common among those who were offered reconstructive surgery, and many of the men concurred with Matthew’s comment: “it will always look like a reconstruction, you will never look natural again, you will never look as you were” (lines 230-231). The men’s doubts about the appearance of a reconstructed breast was typically the top influencer effecting reconstruction-based decisions; these doubts perpetuated by the fact that most men had never seen a reconstructed male breast, thus the threat of the unexpected seemingly outweighed the perceived possible benefits.
Other men (as do some women), however, simply viewed reconstruction as an ‘unnecessary’ additional surgery that could potentially further threaten their self-image, and indeed their mortality, as Michael said: “if it’s an operation that I don’t have to have I ain’t havin’ it not just for cosmetic purposes” (lines 490-491). Eammon also shared this view, but unlike Michael, expressed bias towards female patients:

“I understand why women want it but surgery takes so much out of you there’s so many things that can go wrong even with minor surgery I think you should never have surgery unless you need it people are mad that have cosmetic surgery”

(Eammon, lines 1648-1652)

His comment that reconstruction is understandable in women but “unnecessary” in men, to an extent, echoes the negative reactions of some clinicians that some of the men described; further illustrating the self and other stigma affecting men with breast cancer, and how this serves to disempower them. Interestingly, both men position breast reconstruction as a want rather than a need for men, underestimating its potential worth beyond aesthetic value.

Incongruent with (most of) the men’s self-confessed body image struggles post-mastectomy, several men attempted to exert their masculinity by articulating breast reconstruction in men as needless; some stoically suggested men should learn to accept their changed bodies, while others described reconstruction for men as “ridiculous” (Walter, line 207), linking it to vanity – a typically non-masculine trait. However, one man did express regret at opting-out of reconstruction when it was offered to him; believing that it may have liberated him from the threatening experience of being shirtless post-mastectomy:
“If I’d had reconstruction maybe I would have felt freer to take my shirt off... I would tell people to go for reconstructive surgery”

(Kevin, lines 318-319, 1142)

6.4 Physical reminders – The embodied breast cancer experience as a man:

“you take your shirt off and it brings it home to you” (Robert, line 681)

This subtheme articulates the men’s meaning-making regarding bodily changes brought about by breast cancer occurring; what these changes mean for the men in terms of their physical capabilities, self-perceptions and self-image, in view of social and cultural understandings about traditional (Western) male body norms and ideals.

Adjusting to their altered embodiment and coping with physical reminders of the breast cancer experience, such as a changed appearance, loss of libido and reduced physical strength, was articulated by the men (as it is some women) as one of the biggest challenges they faced. Though some took pride in their body’s ability to overcome the life-threatening illness, the men typically expressed negative sentiments about their post breast cancer bodies; many mourning the loss of their former physical appearance, dissatisfied with their resulting body image (Mishkind et al., 1986). The men exhibited a range of emotions with respect to their changed bodies, from feeling incomplete: “you’ve got a part of yourself missing” (Andy, line 407), and embarrassed: “as long as no one sees it” (Darren, line 670), to sheer despair: “I hate looking at myself” (Eammon, lines 2877-2878). The men’s discussions about the impact of breast cancer on their male bodies and embodied masculinity can be grouped into three broad categories: physical aesthetics, physical performance and physical restrictions.

Physical aesthetics, or rather the changes breast cancer imposed on the men aesthetically, was commonly discussed. For most, their physical appearance embodied their masculinity; serving
as a visual representation of their male gender membership. Therefore, deviation from embodied masculine ideals and norms was generally viewed with great negativity, hence the men’s discontentment with their post breast cancer bodies; the lack of symmetry and scarring, among other changes, highlighting the difference between a typical healthy-appearing male body and their own, indicating their subordinate male position post-illness (Connell, 1995).

The physical impact of breast cancer on the men’s bodies was individual and varied case by case; therefore, the perceived aesthetic threat to their male identity was greater for some than others, while scarring and hair loss presented as the most influential and talked about appearance-based changes.

Scarring from undergoing breast cancer treatments undoubtedly had the greatest impact on the men’s body image perceptions. Though some of the men were outwardly nonchalant about their scarring claiming “it doesn’t bother me” (Maurice, line 1118) and attempted to normalise scarring on men’s bodies: “I’ve had scars forever anyway, so what?” (Paul, lines 1004-1005) – possibly to protect their masculinity (discussed further in Chapter 7); many demonstrated vulnerabilities with respect to their scarred bodies, daunted by the perceived threat of appearing different to male body norms and/or others thinking them female, given the scar’s embodied position: “they might think was he a woman at one time?” (Kevin, line 608).

When talking about the negativity attached to their scars, the men often used extreme language to express themselves; like Eammon, who was especially self-critical of his post breast cancer body:
“I think it’s absolutely bloody awful it is so ugly looking but that’s what it is (...) basically I can’t stand in front of the mirror and look at that even I’ll go in the bathroom take off my shirt and sort of look round the bathroom as I’m doing it then pull the t-shirt on... it’s my perception more than anything else... because it’s mine...I have a kink about it I can’t get over”

Image 8, Scarring, Eammon (lines 2843/2844)

Eammon commenting that “it’s my perception... because it’s mine” implies that the threat he senses comes from within rather than external sources, reflecting internalised stigma and lack of adjustment to his changed appearance. In his account, Eammon goes on to discuss how his body dissatisfaction post breast cancer disrupts his lifeworld in various ways, from being intimate with his partner: “we slept naked before the op I couldn’t do that now I have to have the t-shirt on” (lines 1264-1265, 1267), to gym-related practices: “I’ll go home to like change and get showered now” (lines 1295-1296); these admissions suggesting that he is concerned about how others perceive his scarring too, and that his relative meaning-making goes beyond his own self-perceptions.

Many of the men discussed adapting their behaviours to prevent themselves and others seeing their breast cancer scars. This included avoiding mirrors, constantly covering up with clothing declining to participate in activities that involve being topless, and only undressing in private;
practices which had become habitual but burdensome overtime – physically and mentally – as Neil and Kevin discussed:

“That was a lovely ‘oliday the negative though was ‘avin’ t wear a t-shirt all o’ the time I was there... but it’s just the way you feel”
(Neil, lines 2274-2276)

**Image 9**, Having to wear a t-shirt,
(Neil (lines 2275/2276)

“If I take my shirt off I put a shirt or a towel that side () I have to () I make sure I drape something that side () I’m very conscious that its covered up... it’s in here [mentally] it bothers you... I miss out on enjoying myself a lot () not as much freedom as I would have if I could just whip my shirt off... it’s made me crawl inside myself... it’s not something you don’t notice because you’ve had it for so long you notice it each time you look in the mirror”

(Kevin, lines 565-579, 602, 892-894, 916-918)

Kevin articulates his scarring as a lasting undesirable restriction preventing him from living the embodied life he desires; a psychological problem impinging on his post breast cancer
behaviours. Though this is not an exclusively male breast cancer experience, the point both men make about having to rethink and behave differently in situations where men are usually topless is almost exclusively a male experience. Kevin’s comment “it’s made me crawl inside myself” indicates the introverting effect his altered embodiment has on his social-self, particularly in male-dominated settings, as illustrated by his decision not to disclose his breast cancer to his co-workers for fear of being ridiculed: “men are men they don’t see anything as hurtful to people it would’ve been a continuous joke...it wasn’t the disclosure of the cancer it was the disclosure of having the nipple removed...it would’ve just become a joke for them to play on like oh you’ve only got one you’re half a man or whatever” (lines 73-75, 422-425).

Many men were cautious of other men knowing about their breast cancer, particularly men seeing their scarred breasts; but unlike Kevin, not all could articulate why the perceived threat from men was presumed greater:

“I’m more embarrassed by men seeing my scar than women I don’t know why”

(Geoff, lines 1205-1206)

It could be that Geoff has developed an inferiority complex where other men are concerned given his atypical male body image, possibly perceiving men to be more critical of his male body and inquisitive as to how he acquired his scar than women; perhaps supposing that women will be more understanding and empathic about breast-related aberrations. Either way, together with Kevin’s comment, Geoff’s remark serves to illustrate the specific concern the men showed regarding other men’s perceptions about their masculine embodiment post-illness.

Much discussion also centred around changes to the appearance of the men’s hair following breast cancer treatment. Some men considered hair loss an insignificant part of the embodied
male breast cancer experience, claiming this to be more of a concern for female patients and in turn downplaying the impact on men: “I ain’t got much anyway so it don’t make much difference to me but for the ladies it’s a big thing” (Geoff, lines 353-356). Others however said losing their hair had a profound psychological impact, as well as threatening their physical appearance. In some cases, the men became visually unrecognisable from their pre-breast cancer selves, inducing feelings of vulnerability and loss of identity. For instance, Jason recalled how a friend failed to recognise him without hair:

“I’d had all ma hair shaved off and I’m sat in this empty bar waiting for friends and one of them walks in I’m only about five ten yards in front of her and she walked straight past me (. ) didn’t recognise me... I had a little laugh and a joke about it but it actually hurt a little bit... do I change that much does a little bit of hair make a difference? (. ) sort of brings it home t’ you that your appearance does matter t’ people it makes a difference to how they see you”

(Jason, lines 565-570, 574-575, 579-580)

Emotionally moved by the realisation that his physical appearance is an integral part of his identity insofar as how others perceive him, Jason asked rhetorically “does a little bit of hair make a difference?” disconcerted by how, in his eyes, a minor aesthetic change can be so impactful. Not only did the men discuss instances like this where others failed to recognise them, some also expressed difficulty in recognising themselves; struggling to identify with their changed appearance, both during and after treatment, like Tom:
“I look like an alien... it’s (.) someone else really (.) it doesn’t really look like me... no it’s like someone else it’s extremely weird looking at it... I ‘ad big bushy eyebrows lovely eyelashes a head a hair (.) the lack of ‘air still affects me (.) fact”

(Tom, lines 1739, 1757, 1839-1840)

Image 10, Chemo, Tom lines (1738/1739)

In his account, Tom compares this photograph to one of himself pre-diagnosis to visually illustrate the impact of chemotherapy on his appearance, focusing specifically on losing his hair and the personal meaning of this, having always had and been known for his “lovely head of hair” (line 512) pre-breast cancer. For Tom, his hair was a defining feature of his embodied male self, especially his “big bushy eyebrows” which, stereotypically, are synonymous with masculine embodiment, hence the unfamiliarity he experiences when looking at the above image and seeing somebody different from the man he previously self-identified with.

A number of the men expressed their aversion to presenting as “him with the breast cancer” (Ed, line 1107) wanting others to recognise them beyond their illness; like Michael who actively tried to engender this by disguising his hair loss:
“the first time I went out I made the mistake and I’ll say mistake of wearin’ a cap
because it drew attention to me an’ I remember over hearin’ a friend of mine talkin’ to
somebody sayin’ “well he’s got cancer that’s why he’s wearing a cap” and from then
the cap went”

(Michael, lines 423-427)

In trying to distract from his changed appearance, in reality, Michael wearing the cap attracted
unwanted attention, causing him to feel exposed when the opposite was intended. His
decision to stop wearing the cap suggests he felt threatened by his perceived association with
the stereotypical appearance of a cancer patient, i.e. a bald head hidden by headwear; perhaps
wanting to disassociate himself from this alternate uninvited identity he perceives to affront
his self-image.

Beyond discussions about changes to their physical aesthetics, the men also discussed
experiencing changes in their physical abilities too. Many articulated feeling “out of
condition” (Ken, lines 849-850) following undergoing breast cancer treatment and frequently
drew comparisons between their pre- and post-illness physical selves, noting stark reductions
in their bodily strength and capabilities; this preventing them from conforming to socially
constructed male abilities, and infringing their sense of masculinity. Most men viewed their
pre-breast cancer body as superior to their post-illness physique, believing that their inability
to perform physical tasks previously done with ease undermined them as men (see Mishkind
et al, 1986); like Darren, whose reduced physical strength since affects him working as a
builder:
“The lads laugh at me trying to get up the scaffold... because I used to be like them shoot up trees and hang off scaffolding I was that nimble and that's the difference what breast cancer did to me (.) I was that to this”

(Darren, lines 870, 876-878)

Realising that he is less physically able than his pre-breast cancer self, and also his male co-workers, Darren illustrates here how his reduced physical prowess serves to threaten his masculinity and sense of self; his breast cancer distancing him from hegemonic masculine ideals by hindering his enactment of typical male abilities.

Related to changed physical performance, several men also discussed experiencing reduced sexual performance and loss of libido post-diagnosis; this also serving to threaten their male identity, since male sexual potency remains to be a central component of hegemonic masculinity (Collier, 2002), and also marital contentment (Javed, Gul & e-Siddiqa, 2016). Recognising this, Peter commented: “I'm lucky that I have a good wife who understands” (lines 514-515), indicating his awareness of the potential threat his sexual dysfunction poses to his spousal relationship. Jonathon was equally conscious of how his low libido affected his wife:

“That’s very painful for her she hopes that it might be regained erm (.) I don’t think I’m interested... but I can still get an erection”

(Jonathon, line 586-587, 594-595)

Jonathon highlighting that it is his sexual drive rather than functioning that is affected implies he perceives dysfunction to pose a greater threat to his masculinity and assumed male ability than desire, which he almost positions as a choice. Also, in focusing on how his wife is
affected, he deflects attention from his own meaning-making; perhaps purposefully as an act of self-preservation, given the exposing potential of discussing sexual performance problems.

Further to performance-based concerns, some men also had doubts about whether their romantic partners would be sexually attracted to their changed body, as Matthew explained:

“I’ve always been a very sexual person and I was concerned that it didn’t affect my overall attractiveness to another person and one of the things that I did within the first year was I had a couple of affairs (.) it was almost like a statement that I was a survivor that I was still alive”

(Matthew, lines 360-364)

Aware that his wife’s reasons for wanting to have sex with him were perhaps deeper than superficial attraction, Matthew described how he purposefully sought sex with strangers post-illness to establish their meaning-making of his body’s “unusual state” (line 378); directly confronting the perceived threat of appearing sexually unattractive to determine the effect of breast cancer on his male attractiveness, which he proudly confirmed was slight, if any: “it wasn’t part of their decision making whether or not they slept with me” (line 387), self-affirming his virility beyond breast cancer.

Physical restrictions imposed on the men as a result of their breast cancer treatments were also discussed. Skin tightness, muscle loss, and fatigue (all of which affect women too – Breast Cancer Care, 2017) presented as the most common physical restrictions the men experienced; all impinging upon them expressing their male selves post breast cancer. For example, participating in certain sports, for some, was no longer possible: “I don’t think I’ll ever be able to play badminton again I couldn’t lift me arm up” (Geoff, lines 461-462), while others expressed having difficulties fulfilling family roles, both aspects frequently reported by
women (Waring, 2000); particularly struggling with the physical aspects of caring for children, as Ewan noted:

“I’m not able to carry him or t’ do this an’ that with ‘im... I can’t carry him this side at all the scar tissue won’t allow me it’s too painful...my son doesn’t understand that I still have problems because I’ve never shown him a problem til now...handling the young baby”

(Ewan, lines 865-874)

Ewan explained how the non-visible nature of his restrictions coupled with him concealing his difficulties leaves him vulnerable, causing others to question his physical ability and his masculinity relatedly. He also reflected on the emotional implications of not being able to perform as a typical grandfather would but marginalises men by supposing that “from a woman’s point of view that’s probably more emotive” (lines 875). It is important to note here that these experiences are not exclusive to men, with many women experiencing similar physical issues (Verloop, 2000; see also 9.3).

Another hidden restriction the men discussed was the persistent fatigue they experienced throughout the breast cancer episode and beyond, resulting from both physical and psychological causes; hindering them from performing masculinities as they did pre-breast cancer, as Robert explained:

“The tiredness is phenomenal...I get amazingly tired just walking uphill it doesn’t stop me but I do find it emotional there’s no denying it y’know men are not superheroes have these things an’ just get on with it and move on... the reminders are always there”

(Robert lines 574, 676-685)
Robert’s comment “men are not superheroes” opposes the social expectation that men are fashioned to be stoical and unaffected by adversity (Brunt, 2013), highlighting the pressure men perhaps feel in trying to live up to this, and the perceived threat to their masculinity if they do become affected, especially emotionally. This could be why some men claimed breast cancer, particularly the embodied experience, had little to no emotional impact: “it didn’t worry me at all” (Maurice, line 309). However, as Peter suggested, it may be that men are unconscious of the emotional effect breast cancer has on them, rather than simply dismissing it:

“I think I was tired for two years afterwards... you are affected by it psychologically whether you feel like that or not”

(Peter lines 428-432)

6.5 Breast cancer as a constant – lasting impressions of the illness episode:

“it’s always there” (Kevin, line 850)

This final subtheme reflects the men’s perceptions of threat insofar as the perceived permanency of breast cancer in their lives once diagnosed, indicating the illness to leave lasting impressions, infiltrating the men’s lives in various ways; physically, vis-à-vis their changed masculine embodiment; cognitively, influencing their self-conceptualisations; socially, impacting on their identities, relationships and behavioural practices; and emotionally, impinging on their psychological adjustment to illness and back to health. This threatening to recurrently compromise the men’s sense of self and masculinity, beyond the immediate illness event.

As the men were all at different stages of their breast cancer journeys at the time of interviewing, the extent to which breast cancer occupied the fore or background of their
psyche varied. Yet, regardless of their stage of illness, all concurred that breast cancer played a constant role in their lives, with reminders – both physical and intangible – recurring across all domains of life. By and large, the perceived omnipresence of breast cancer was articulated by the men as unnerving and unwelcomed, with most interpreting it as an ever-present and abiding threat. Jonathon, for example, visualised breast cancer as if it had taken the form of an unidentifiable attacking “creature”; its red colour signifying threat and danger, and the globe-like chaotic mass beneath representative of his lifeworld coming under attack:

“the cancer’s always there lurrrking (. ) my own interpretation of it is this red creature... that’s a cancer cell which is attacking me the green object beneath and that’s my confused state...”

(Jonathon, lines 738, 1574-1575)

*Image 11*, New horizons, Jonathon (lines 1527/1528)

Similar to how Jonathon depicts breast cancer as something ominous and hanging over him, Bill also senses this, but chooses to represent this alternatively using a cloud:
Images of blue skies with white clouds are typically understood to correlate with positivity and good emotional health and wellbeing, serving often as a popular visual in mindfulness training and stress management techniques. Thus, at first-look, this photograph could be perceived to represent positive elements about Bill’s breast cancer experience. However, “The cloud” is indicative of complex meaning-making, a metaphor for his breast cancer; Bill commenting on “how it hangs over you all the while” (lines 1345), clouding the mind, “always there’ yet ‘isn’t taking it all up” (lines 1357, 1401), as reflected through the patchy incomplete appearance of the clouds and areas of clear sky. Cognisant of his breast cancer’s incurability with the disease having now metastasised, Bill explained how knowing this is “adding to the cloud” (line 1388), and how the cloud occupying the sky is symbolic of the illness invading his life and daily cognitions: “I thought it was a way of explaining that back-of-the-mind thought that you get every day” (lines 1394-1395), indicating its constant impact.
It is also indicative of the men recognising their subordinated male positioning, as they present themselves as less powerful and physically beneath both the cloud and creature.

Further conveying the perceived constancy of breast cancer in his life, when giving his account, Bill presented “The cloud” in conjunction with a photograph of a carriage clock, titling this “Time”; the two together representative of his meaning-making pertaining to spatiotemporal aspects of the breast cancer experience. Time, like breast cancer, beyond his control, and thus incongruent with hegemonic masculinity, of which control is a central aspect (Connell, 1995):

“*It’s to represent time yes (*) what is in your mind mostly when you have breast cancer is how much time have I got... it’s at the back of your mind, how much time is there, what is going to happen tomorrow, the next day...*”

Bill, lines 1424-1425, 1430-1432

*Image 13,* Time, Bill (lines 1422/1423)

Like “The cloud”, Bill uses this image to visually exemplify the consuming effect breast cancer has on his life, and how his ill health is never far from his conscious thoughts; prompting greater emphasis on time, and how this currency is spent, with a particular focus on “*what time can do or give you*” (line 1664). Bill articulated that although the threat of time
running out, i.e. mortality, is something that impends all mankind, developing breast cancer
gave greater prominence to this threat and his remaining lifetime, commenting: “you are not
quite as sure as you would be if you hadn’t got the cancer of the time in front of you” (line
1443-1445); a feeling he portrays as ongoing and unrelenting.

In addition to discussing breast cancer as a constant relative to spatiotemporal matters, as
earlier mentioned (see 6.4), the men spoke at length about physical lasting impressions of the
breast cancer diagnosis, with reference to their changed bodies post-treatment, and the threat
this poses to their future male identities. For instance, Matthew described how his post-
mastectomy body serves as a “constant reminder” of the breast cancer episode and his
permanently “different” embodied self:

“to look at my body is very different because I only have one breast so that’s a
constant reminder of the fact I’ve had breast cancer and that I’m a bit different”

(Matthew, lines 738-740)

Kevin also articulated having a constant awareness of his changed body, reminded about his
breast cancer experience on a daily basis, simply by performing standard everyday practices
such as undressing and showering:

“…every day I am aware of it... it’s always there because I am taking my shirt off
every time I have a shower or I go to bed and you do check yourself I never stop
checking myself”

(Kevin, lines 846-852)

Kevin’s remark here about regularly self-examining his body after the illness event reflects
another lasting impression of the breast cancer experience, with the potential threat of
recurrence consistently a concern among the men interviewed, and indeed many cancer patients:

“it never goes away... you can have whatever surgery you like but it’s still there with you y’know almost every time you cough you think oh my god this is something else it’s coming back... you always live with it”

(Robert, Int 2., lines 154-157, 301)

Articulating the lasting psychological effects of the breast cancer episode, Robert explained how regardless of the disease being physically treated, the mental and emotional impacts of the illness persist; having the propensity to influence how men think about their future selves, their lives and their masculinities. For instance, as Tom discussed, from his perspective, breast cancer – in part – defines the man he is today:

“your life changes irrevocably because it defines ya I’m a lot of things I’m the guy in the band I’m a loud mouth bad joke teller I’m the chairman of the LOFC fans trust but of all of it I’m the guy who had breast cancer”

(Tom, lines 1215-1218)

Illustrating how his identity comprises multiple aspects, including being a “guy” and also holding the position of chairman – both of which reflect his male hegemony – Tom explained how being “the guy who had breast cancer” gives him an identity that supersedes all his other identities, permanently changing the way both he and others perceive him post-diagnosis; articulating this as “life changing stuff” (line 1228), demonstrating how the breast cancer diagnosis exposed his vulnerability and leaves him in a threatened position, personally and socially.
Further exemplifying the ways in which a breast cancer diagnosis continues to place men in a threatened and exposed position beyond diagnosis and treatment, the men discussed multiple instances where their breast cancer history invaded their present lives. For example, several men mentioned how having breast cancer impacted on them taking out personal indemnities, e.g. life cover and holiday insurance, long after the illness episode; a common experience for many cancer patients:

“I’d finished the treatment and y’know as far as I was concerned I was on the road to getting better but institutions don’t actually see it like that... you have to declare you’ve had breast cancer on your forms”

(Geoff, lines 758-760, 779)

Geoff’s comment here implies that he, and others affected by breast cancer, are repeatedly penalised by their breast cancer history, preventing them from moving fully beyond the illness event. Furthermore, as the men discovered, such implications of the breast cancer diagnosis reached far beyond themselves; having the propensity to negatively affect their families’ futures too, as Robert discussed:

“...she was saying to me “have you got children? can I suggest you take out life cover for them” (.) because she said they will find it very hard to get life cover in the future”

(Robert, Int 1., lines 1094-1096)

Both extracts serve to demonstrate the pervasiveness of breast cancer, or as Jonathon described it “the tentacles of this bloody disease” (line 707), revealing its omnipresence not only in the men’s lives, but potentially in the lives of their offspring too; continuing to threaten their masculinity insofar as hindering the men’s capabilities to protect themselves and their progenies.
Another way the men articulated the constancy of breast cancer in their lives was through linking the illness event to other maladies and/or side effects that they continue to live with subsequent to having breast cancer, including lymphedema; temporary or permanent swelling resulting from damage to the lymphatic system, typically caused by breast cancer treatment. Several of the men reported experiencing lymphedema, including Eammon whose symptoms are permanent, requiring him to wear a compression sleeve for symptom relief on a daily basis:

“it’s now second nature I find it strange when I don’t have it on... it’s the first thing that goes on even before I put my glasses on my sleeve and the last thing that comes off at night... it’s always there... I have to live with it now”
(Eammon, lines 2703-2704 2706-2707, 2714, 2722)

Image 14, Sleeve, Eammon (lines 2701/2702)

Eammon’s comment here specifies how wearing the sleeve has become an essential part of his daily routine, prioritised even above wearing his glasses, and customary to the extent that he feels “strange” without it, indicating its steadfastness. Furthermore, when not wearing the sleeve, Eammon admitted that he becomes more aware of his physical deterioration: “if I
didn’t wear the sleeve (.) I’ll be honest with ye... I can’t do much” (lines 2720-2721, 2726); this he finds harder to accept than the visuality of the sleeve, preferring to appear aided by the support garment as opposed to physically incapable, believing this to be a lesser threat to his masculinity.

Some of the men added to the visual constancy of their breast cancer experience by opting to have breast cancer themed tattoos; possibly because tattoos – at least traditionally in Western contexts – are strongly linked to machismo:

“that’s why I ‘ad the tattoo done they’ll look and that’s the first thing they’ll see then under the scar I’ve got I’m a survivor so they know then why it’s there and what it was without me having to explain”

(Neil lines 385-386, 390-391)

Paradoxically serving as both a distraction and reminder, Neil’s breast cancer tattoo simultaneously covers the reality of the embodied breast cancer experience (see 6.4) whilst attracting others’ attention, having the potential to both preserve and expose his masculinity. Though he considers the tattoo is self-explanatory, averting unwanted discussions about his uncommon male bodily appearance, equally it has the propensity to invite conversation providing a permanent talking-point; furthering breast cancer’s constancy in his life.

Making sense of their breast cancer’s lasting impressions, for some, proved more challenging than dealing with the diagnosis:

“it not the fact that you’ve had cancer but the fact that it just won’t go away... it never goes away you never escape it”

(Michael, lines 971-972, 1313)
Like Michael, Ed also articulated feeling unable to free himself from the shackles of a cancer diagnosis; positioning cancer as superior to other illnesses and more impactful, and therefore difficult to be “done with”:

“If you think of some illnesses people ‘ave y’know it’s done with and put in a box and then they go onto the next thing (. ) cancer seems t’ stay with ya”

(Ed, lines 161-163)

Though Michael and Ed’s comments here refer to cancer diagnoses generally and not breast cancer per se, nevertheless both also acknowledged that developing an unusual male cancer made their illness experience particularly unforgettable: “I’ll never forget it” (Michael line 339).

6.6 Chapter summary

This chapter has introduced and explained the schematic representation of masculinity serving as the framework for the analysis, outlined the three superordinate masculinities identified, and discussed the first of these interconnected themes – threatened and exposed masculinity – and the corresponding subthemes in depth. As explained, the men seemingly transition between the three masculinities identified across the breast cancer episode, and typically perform threatened and exposed masculinity first in the earliest stages of illness, as they begin to make sense of their ill-health, the diagnosis, and how this effects their male identity. The men’s portrayal of threatened and exposed masculinity as breast cancer onsets is reflected through their verbal-visual representations of felt and enacted marginalisation; perceived and actual clinical vulnerabilities; meaning-making of the embodied breast cancer experience; and the perceived permanency of breast cancer in their lives following the diagnosis. Together, this is shown to impinge on the men’s sense of self and masculinity, working collectively to
challenge well-established and previously taken-for-granted assumptions the men had formed about their constructed male selves over time, prior to developing breast cancer, resulting in masculinity threat.

In the next chapter, attentions are turned to the second of the three masculinities identified, protected and asserted masculinity; first explaining its relationship to the schematic representation and the other masculinity themes, before discussing how and why men with breast cancer express this masculinity, and what it represents.
Chapter 7 – Analysis – Superordinate Theme Two: Protected and asserted masculinity

In the previous analysis Chapter (6), the concept of men presenting a threatened and exposed masculinity relative to the experience of breast cancer was considered. Specifically, how and why men feel threatened and exposed from the onset of illness, even before the confirmed diagnosis is received, and what developing breast cancer means for their masculinity. In this chapter, and also the one that follows, the focus shifts to consider how men’s cognitions and behaviours adapt having acknowledged their threatened-exposed position; initially in defence of their masculinity, then later as they look to accommodate their changed male selves (see Chapter 8). Here, the men’s reactive performance of a protected and asserted masculinity is analysed and discussed, as their transitioning across the breast cancer trajectory, self-evaluations and meaning-making are explored further.

As Connell (1995, 2000, 2005) has discussed, masculine identity plays a significant role in men’s health behaviour, and given masculinity’s fluid nature, it is perhaps best to consider masculinity as plural rather than a single entity, shifting over time and place. In the context of men with breast cancer, both suppositions are supported. The trajectory of breast cancer, as previously discussed (see Chapter 3, and Quincey et al., 2016) is complex, with little understanding of the illness course experienced by men, or their ongoing issues and needs. Subsequently, men feel marginalised, and at the periphery of optimal care and support; leading many, or at least those who aspire to hegemony, to realise their biggest fear, i.e. being perceived as powerless and vulnerable by others. Thus, in navigating their way through the breast cancer episode, men seemingly transition between masculinities as they see fit in working to preserve their male identity, while simultaneously managing and making sense of the critical illness event.
The expression of a protected and asserted masculinity typically comes after the men recognise their threatened and exposed positioning as men with breast cancer, as they work to defend themselves against the relative masculinity threat. Having by this stage realised breast cancer’s undesirable effect on their performance of usual male roles and abilities, and recognised its propensity to compromise their emotional stability, the men appear to search for what they consider to be effective ways of concealing breast cancer’s influence on their masculinity, and for upholding their male identity. Generally, this included giving an impression of normality despite their changed health status; downplaying breast cancer and downwardly comparing to others’ experiences, and other illnesses; dismissing their need for help and support; claiming male behaviour to be the cause of their breast cancer; and exerting their manhood by highlighting male traits, all of which collectively served to preserve their sense of self as a man (Courtenay, 2000).

Constructions of traditional masculinity do not permit men to be expressive in their illness behaviour (Robertson, 1995), and, many of the practices women are praised for performing are typically met with sociocultural disapproval when performed by men, e.g. seeking help (Courtenay & Sabo, 2001). Not surprisingly then, men who conform to traditional male codes and norms may prefer to face risk and physical discomfort rather than deviate from male gender-appropriate illness behaviours (Galdas, 2009), fearing that alternative practices may threaten their masculinity; something which they strive to protect themselves against. As Verdonk, Seesing and de Rijk’s (2010) research showed, from the hegemonic male’s perspective, the ideal ‘real’ man is a winner not a whiner; in other words, he is invulnerable competitive and successful, and does not complain when faced with adversity. Hence, men who look to adhere to this construction of masculinity are unlikely to disclose feelings of vulnerability and/or seek support from others, as demonstrated across the men’s breast cancer
accounts; many of whom purposefully sought ways to showcase their winner status and independent coping styles so as to protect and assert their masculinity. Examples included for instance setting themselves – and importantly achieving – goals, usually of a physically challenging nature; providing help and support to others; and presenting themselves to be in a more favourable position than counterpart patient-survivors (men and women).

Five corresponding subthemes were identified in relation to this theme and provide further evidence for the men performing a protected and asserted masculinity consistent with a breast cancer diagnosis:

**Table 10. Subthemes for Superordinate Theme Two**

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7.1 ‘Being’ male – reasoning why he developed breast cancer: “well otherwise, why?” (Derek, line 1380)

This first subtheme illustrates the men defending their position as men with breast cancer and asserting their masculinity by reasoning that disease onset occurred as a result of ‘being’ male; developing due to performing behaviours more commonly associated with men, e.g. contact sports, physical violence and risky health practices.
Not at any stage of the interview were the men explicitly asked why they thought they had developed breast cancer, yet interestingly, most men offered reasons as to why the illness might have occurred; suggesting it was perhaps important to them to establish a cause in making sense of their illness, and equally, to quell some of the ambiguity which typically surrounds a diagnosis of breast cancer in men. For instance, several of the men reported having a family history of breast cancer in either a first- or second-degree relative(s), leading many to presume their breast cancer had a hereditary cause, resulting from, as Colin referred to it, a “rogue gene” (line 906). Some still maintained this even when no BRCA link could be definitively determined: “I never knew me dad ... it must’ve come from me father’s side cos there’s no record of it on me mum’s” (Neil, lines 57-62). This implying that the men were accepting of genetic explanations, perceiving heritable factors as a legitimate reason for a man to develop breast cancer in their search for meaning (Taylor, 1983).

More often than not though, the men tended to attribute their breast cancer to external reasons, possibly in an attempt to preserve their constructed masculinities; as externalising the cause circumvents questions about the functionality of their male bodies. Specifically, their reasons reflected a protected and asserted masculinity; the men between them listing a host of different stereotypically male traits and behaviours which, despite having no real evidence for, they causally attributed to either the onset or discovery of their breast cancer. As Taylor (1983) noted, causal attributions and meaning-making go hand-in-hand, especially in cancer patients trying to understand why the health crisis occurs; as understanding the cause can help them to understand the significance of the event, and what this means in the context of their lifeworld. For men diagnosed with breast cancer, the search for causal meaning is particularly important for understanding the implications for their masculinity. In ascribing the event to male practices and depriving their breast cancer of female characteristics, correspondingly,
the men masculinise the diagnosis; enabling them to preserve their sense of identity and uphold their male credentials.

Reasoning why he developed breast cancer, the men suggested a variety of masculine explanations for the illness occurring, including both physical and psychological factors; many of which the men articulated to be within their control, inferring a belief in their ability to manage the illness and/or prevent recurrence, affording them a sense of mastery (Taylor, 1983). Regarding physical aspects, a number of the men inferred that their breast cancer resulted from being exposed to dangerous working conditions, asserting their masculinity by highlighting the risk attached to their male work roles; like Roy, who suggested his breast cancer may have been attributable to him experiencing radiation exposures when working for the military:

“when I was working on the submarines we were doing an exercise that meant going into the radioactive department and doing a survey and... while I was in there I was exposed to a very high level of gamma and probably some neutrons... I believe that was the cause”

(Roy, lines 371-372, 382-383, 385)

Radiation exposure is a well-documented risk factor for breast cancer in women (Barcellos-Hoff et al., 2013) and has also been shown to increase risk in men (Thomas, Rosenblatt, Jimenez, McTiernan, Stalsberg, Stemhagen, et al., 1994). Nevertheless, irrespective of previous links made between radiation and breast cancer, it could be argued that Roy – and other men – reasoning that their breast cancer ensued from performing such dangerous duties, serves to both protect and assert their masculinity; protecting it by highlighting their conformity to stereotypical male practices, like engaging in risky behaviours, and asserting it
insofar as demonstrating the high-risk nature of jobs typically performed by male military personnel.

Like Roy, Derek also served in the military, and similarly, he reasoned that his breast cancer was the result of an experience he underwent as an infantry soldier, postulating physical trauma to be the cause; specifically, injuries to his upper body which he sustained from engaging in violent combat:

“I was serving in Northern Ireland on what they now call a black op... there was 8 of us I was the only one that survived... I was left for dead (.) both my legs broken I’d been furiously kicked punched and everything else and having spoken to Dr V about it he said well it prob’ly occurred because all the tissue around the breast had been destroyed...

I suppose this is memories of possibly where the breast cancer started”

(Derek, lines, 261-262, 264, 266-268, 1730-1731)

Given that breast cancer research (in women) has previously indicated a link between physical trauma and onset of the illness (e.g. Rigby, Morris, Lavelle, Stewart & Gatrell, 2002), there may be some substance to Derek’s claim. Still, his reasoning can also be interpreted as an attempt to protect his masculinity, as again it demonstrates his adherence to male-typical roles and practices. Further, Derek pointing out that he was the only one to survive indicates a
sense of invincibility and also superiority over the other men, given his capacity to withstand the extreme violence, and later the breast cancer episode. Furthermore, the photograph he uses to visually represent this reasoning is also interpreted as being purposefully masculine, displaying weaponry and military uniforms, representing camaraderie and brotherhood in contrast to typical breast cancer imagery, which tends to reflect femininity and sisterhood (Sulik, 2011); thus, upholding his male identity.

In addition to attributing their breast cancer to physical risks associated with their male work roles, some men also postulated their breast cancer to be the product of work-related psychological factors, including job stress, like Eammon:

“I’ve been told by all the doctors it was just a chance in a million nothing unusual about my genetic makeup there’s nothing unusual about my oestrogen levels and nothing about my bloods nothing unusual with my body’s makeup etcetera (.) they sort of dismissed stress but I’m not so sure because my job is (.) it’s stressful... I’m the legal director of the company... and I personally do think that stress does contribute to it”

(Eammon, lines 33, 104-108, 2753)

Again, work-stress also presents as a plausible possible cause, given its association with greater odds of cancer in men (Blanc-Lapierre, Rousseau, Weiss, El-Zein, Siemiatycki & Parent, 2016), though not breast cancer specifically. Paradoxically however, men are usually reluctant to believe that stress impacts on their physical health (American Psychological Association, 2011); therefore, it could be argued that men reasoning psychological factors to be the cause in the context of breast cancer is purposeful and protective, since it deters postulations about physiological abnormalities, which men typically perceive as a greater
affront to their masculinity and can be self-managed. Eammon demonstrates performing a protective masculinity in two ways; firstly, by confirming that his male body is functioning normally, suggesting his breast cancer is unrelated to his “body’s makeup”; and secondly, by inferring that his breast cancer is an adverse reaction to the excessive pressures and demands of his high-power working role, which in turn asserts his hegemonic status.

Beyond reasoning factors associated with their male working roles to be the possible cause of their breast cancer, the men also discussed the effects of their lifestyle choices too, referring specifically to hobbies regarded as being typically male, such as binge drinking and playing sports, as Michael and Eammon exemplified:

“it did make me look at myself and say yeah you are drinking too much y’know you are being silly erm because there are links to alcohol and cancers y’know and there’s no getting away from that (.) it could’ve been the reason I got it”

(Michael, Lines 1211-1214)

*Image 16.* Pint of beer,
Michael (lines 1851/1852)
“I came from that generation that all played squash and well the amount of knocks that you got y’know the amount of slicing with the racket and the times I knocked my breast and you do wonder sometimes if that caused it”

(Eammon, lines 2747-2749)

In attributing their breast cancer to traditional assertions of masculinity, the men in turn de-feminise their diagnoses, and preserve their manliness in the process; removing the perceived threat of appearing feminine, at least in terms of why the illness onsets. Michael’s quote especially reflects asserted masculinity in that it implies irresponsible health behaviour by way of heavy alcohol use; both of which are often associated with ‘being’ male (Robertson, 2007). Eammon’s sports-related explanation is arguably less convincing, particularly since physical activity has been found to reduce breast cancer risk (Friedenreich & Cust, 2008). Nevertheless, in asserting his masculinity through playing sport, he preserves his self-identity of being a typical male.

Other reasons the men gave for their breast cancer’s occurrence included sustaining injuries when performing male-typical roles in and around the home, such as DIY repairs and gardening; postulating that contusions caused by falling or blows to the chest, for example, triggered the onset of illness, as Colin discussed:

“a year prior I’d come down a ladder the fast way err and the shock o’ that I’m pretty certain is what triggered it... well I’m pretty certain because (.) well otherwise why?”

(Colin, lines 1377-1380)

Colin’s comment “well otherwise why?” implies that he is at a loss as to how he developed breast cancer if the falling incident is not the reason, suggesting that this explanation serves a dual purpose; satisfying his need to establish a cause for his breast cancer – albeit
inconclusive – and protecting his masculinity by inferring his breast cancer to result from performing a typically male task. Though some did not consider such injuries to be the cause of their breast cancer, they explained how these injuries lead them to discover bodily changes which had otherwise gone unnoticed, like Mervyn: “I were down the garden and I bumped myself somewhere here and noticed it was like bruised and felt numb... and I thought well that's not right” (lines 313-315). Again, detecting symptoms when carrying out every day male roles presents as more masculine than practicing intended breast self-examinations, which many men say they fail to do, admittedly because they are male (Breast Cancer Care, 2015).

Not only did the men’s reasoning for why they developed breast cancer reflect a protected and asserted masculinity, some further exemplified this by admitting to thinking up elaborate stories to tell people to conceal their breast cancer identity, and especially the reality behind their changed masculine embodiment; like Kevin:

“I have considered telling people I was knifed and somebody cut me across the chest (.) it sounds more dramatic than I had breast cancer and a nipple removed... stabbed because I lived in Israel for eleven years so they might think yes Arabs grabbed him (.) that story sounded better to me going through my mind if I was to tell the men at work it would sound good... that was always my if somebody seen us oh yes it’s an old wound... definitely amongst men (.) I had my breast removed because I had cancer no (.) I had it removed because somebody slashed me across the chest”

(Kevin, lines 362-386)

Similarly, Mervyn explained “I just say I’ve been shot in the war” (Mervyn line 251-252), while Darren said he had toyed with telling people he’d been “attacked by a shark on
What each of these examples illustrate is not only the men’s perceived need to fabricate the truth, but also their desire to bolster their manliness in doing so; attributing their altered embodiment to aggressive and dangerous acts predominantly associated with men, e.g. armed fighting and high-risk activities, rather than breast cancer, thus protecting their masculine credentials. As Kevin remarked, these alternative explanations sound “more dramatic” than developing breast cancer, further demonstrating men to downgrade the illness; another protective practice as earlier mentioned. It also implies that men perceive breast cancer as not striking enough for a man to admit to, which is somewhat paradoxical given the notable influence it appears to have had on the men interviewed.

To an outsider – and probably some insiders – it may seem unnecessary for men to go to such lengths to protect and assert their masculinity in the context of a breast cancer diagnosis. However, individual experiences, particularly regarding others reactions to the diagnosis, varied greatly, as this excerpt from Eammon’s account illustrates:

“one person asked me and I really really came down on them she said to me “do you think you might’ve got breast cancer because you’re gay?” now I’ve never had any sort of problems about being gay but... I said to her “no you stupid bitch” ... it was so ridiculous”

(Eammon, lines 1212-1215, 1223-1224)

Eammon perceives the woman linking his breast cancer to his sexual orientation to doubly affront him, seeing this as a slur on both his male and gay identities; hence his sharp rebuke to the comment which serves to reflect the societal ignorance still surrounding breast cancer, and also homosexuality. Remarks such as this indicate why perhaps some men feel the need to
offer masculine reasons for developing breast cancer, and/or to construct stories to conceal ever having the illness, in protecting against the threat of emasculation.

7.2 Maintaining normality: “Business as usual” (Robert, Int. 2 line 52)

This subtheme articulates the men’s desire to continue with life as they did prior to the breast cancer diagnosis; maintaining typically male roles within both professional and personal contexts wherever possible, many even while undergoing treatment, demonstrating a need for control and stability, and an appreciation for everyday practices that perhaps pre-illness they undervalued as part of their male identity.

In defending themselves against the threat of breast cancer, especially the associated masculinity threat (discussed in Chapter 6), the men made various attempts to normalise the illness experience, and particularly the occurrence of breast cancer in men, so as to protect their male identity: “it’s just a disease it’s just an illness” (Paul, line 240), “why shouldn’t men get it?” (Robert, Int.1, line 162). Normalisation, according to Wiener (1975), is defined as any behavioural effort made to maintain habitual life, whatever normal means to and/or is perceived as being by the individual trying to sustain that normality; with strategies including covering-up, i.e. concealing the threat to normality, and keeping-up, i.e. maintaining usual practices – both of which the men demonstrated in their breast cancer accounts. Placing importance on normality has previously been identified in studies of chronic conditions (e.g. Sanderson, Calnan, Morris, Richards & Hewlett, 2011), with normalisation presenting as a common form of protective coping in persons living with various critical illnesses (see O’Neal, 2007), including breast cancer (in women). For example, Hilton (1996) found that keeping-up normality by continuing to perform prior behaviours, de-emphasising sick-role demands and viewing changes as temporary, among other strategies, enabled individuals to perceive themselves as normal despite the strains of their situation, allowing for better
adjustment to the breast cancer episode; a finding which this current study with men lends support to.

Resisting biographical disruption (Bury, 1982; Reeve et al., 2010) by maintaining continuity and delaying shifting from the perceived normal trajectory of their lives to unknown territory saw the men perform multiple behaviours in order to maintain a safe, desirable, and stable state (Hilton, 1996); many of which reflected Knafl and Deatrick’s (1986, as cited in Sanderson et al., 2011, p.619) earlier suppositions about normalising illness. According to Knafl and Deatrick, the process of normalisation in the context of chronic illness has four key elements: “(i) acknowledging the impairment; (ii) defining life as basically normal; (iii) minimising social consequences of illness; and (iv) engaging in behaviour that demonstrates normalcy to others”; all of which was demonstrated in the men’s accounts as they attempt to maintain normal life following diagnosis, as the subsequent quotations and images serve to illustrate.

The men provided various examples of them continuing to practice ‘business-as-usual’ and placed great importance on maintaining normality throughout the breast cancer experience; especially in the early stages of illness, where keeping to plans established pre-diagnosis presented as a key coping strategy for the men interviewed. For instance, coinciding with them receiving their confirmed breast cancer diagnosis, both Robert and Ewan had prior scheduled to take a holiday at the same time – an event which neither man was prepared to cancel or postpone owing to their change in circumstances, as their visual voice representations indicate:
“In the intervening period we went on holiday... to all intents and purposes what I’m tryin’ a show there is that all is well business-as-usual a normal family holiday y’know not a care in the world...”
(Robert, Int. 2, lines 50-52)

*Image 17,* Life was so normal,
Robert (Int. 2, lines 48/49)

“Yeah I thought I’m not gonna lose money on this... so it was put into a compartment in the back of my mind and I just carried on with my holiday regardless I was gonna enjoy myself”
(Ewan, lines 1814, 1833-1835)

*Image 18,* Side, Ewan (lines 1810/1811)

Consistent with previous theoretical suppositions about normalisation (e.g. Wiener, 1975; Knafl & Deatrick 1986), while both men acknowledged the presence of their breast cancer, they presented their lives as normal, and by continuing to proceed with their holidays, their behaviour demonstrated normalcy to others; implying that all is well and concealing the threat posed to their normalities, and masculinities. The men’s decision to go ahead with their holidays is interpreted as a protective practice, in that by outwardly projecting the
maintenance of normality, they deny their illness reality. Further, Ewan’s comment about compartmentalising the information and relative meaning-making away from his immediate thinking is also a defensive practice; though in contrast, this arguably contradicts the implication of life being undisrupted by the diagnosis news, showing him to cognitively engage in efforts to keep-up normality. Furthermore, both men attempt to assert their masculinity here too; Robert, intimating that by continuing as normal with his family holiday he is protecting his family from the disruption precipitated by his diagnosis; and Ewan, by suggesting his decision to go ahead with the holiday was money-oriented above all else. Thus, practicing normalisation techniques as these men did allowed for protection and assertiveness to prevail, serving to defend them and their masculinities against the illness threat.

One area of their lives where the men strived most to maintain normality during the breast cancer episode was in their working lives, placing great importance on being able to continue with their usual work roles and duties; believing that this afforded them much-needed stability at a time when they lacked assurance in other domains of life. The majority of the men interviewed were working on either a paid and/or voluntary basis at the time of their breast cancer diagnosis, and for most, their work role – at least in part – defined the men that they were and identified with pre-breast cancer; providing them with a sense of status, worth, purpose and self-efficacy (Ross & Mirowsky, 1995) – psychological resources which a breast cancer diagnosis potentially threatens, but which they could draw on to defend against the illness threat.

Work, for many of the men, served as a form of escape-avoidance coping (Ghaderi, 2015); offering them an alternative focus and an opportunity to divert attentions and communications away from their breast cancer. Though this may be perceived as a maladaptive strategy (Ghaderi, 2015), those who utilised working as a coping mechanism generally presented as
well-adjusted; possibly because continuing to work throughout the breast cancer episode reduced the perceived masculinity threat, since work is constitutive of masculinity (Gherardi, 1995) and a critical component of male identity. The following examples taken from Clive and Graham’s accounts, both of whom held high-powered working positions at the time of their diagnosis, illustrate how maintaining the daily work-life routine helped to satisfy their need for normality:

“\textit{I coped one hundred percent and that was because I kept on working (.) that kept me busy and I tried to do jobs here [at home] too... I just carried on as normal really... I always was a person to get on with the work so I didn’t think about it a lot really I just carried on working}”

(Clive, lines 640, 697, 711-712)
“whilst I was having treatment just keeping my life as normal as possible and going to work every day helped (.) I worked shorter days but I was in every day and even when I was having the treatment I was doing my emails and so on... it was my sort of coping mechanism... I craved normality... just to stop it controlling my life I suppose... I tried not to let it affect my life is the simple answer by carrying on working as normal and just doing everything as normally as I could”

(Graham, lines 135-138, 142, 144, 148, 589-591)

Both Clive and Graham’s commentaries here indicate that the decision to continue working during their respective breast cancer episodes was very much purposeful; their intention, to regain control and reduce the effects of breast cancer on their lifeworlds by ‘carrying on’ – at least workwise – as they did pre-breast cancer. Clive’s comment “I always was a person to get on with the work” shows this to be the norm for him, and further, implies breast cancer to have had little impact on his ability to work; this protecting his male identity in two ways: firstly, by showing his work-self to be impervious to the illness threat, physically and/or psychologically; and secondly, by continuing to fulfil duties and responsibilities expected of him. Similarly, this is also reflected in Graham’s comment “even when I was having the treatment I was doing my emails”, again showing how usual work practices were uninterrupted by his breast cancer.

As well as striving to maintain normality immediately following the confirmed diagnosis and through their working lives, the men also sought to maintain an impression of normality by continuing to engage in regular leisure activities; especially those with a social aspect to them, and/or typically gendered male. This included the maintenance of various practices; from continuing to be creative and hands-on, e.g. Maurice: “I think that carrying on building the workshop, the gardening, it just helped me t’ survive” (lines 43-44); meeting-up with friends,
e.g. Jason: “it was the highlight of my time off going and seeing me friends or friends round here everybody was always ready t’ go for a beer or have a chat” (lines 694-695); to playing sports, like Matthew who carried on playing rugby, much to the surprise of his clinician and friends:

“He mentioned a couple of times the fact I played rugby so for him as a breast cancer surgeon it must have been quite an unusual thing to say that one of his patients is still playing rugby... people said to me you’ve had breast cancer why you still playing rugby? Because I enjoy playing rugby... as soon as I don’t then I will stop but it’s about that joie de vivre, you know, that I’ve survived and I’m going to carry on with this”

(Matthew, lines 876-878, 948-949, 951-952)

Matthew continuing to play rugby represents his defiance against typical sick-role behaviour, and his refusal to be controlled or changed by his breast cancer. Maintaining his identity as a man who plays rugby alongside having breast cancer serves to both protect and assert Matthew’s masculinity post-diagnosis; preserving his masculine credentials by showing himself to be capable of engaging in the same male behaviours as he did pre-breast cancer, and crucially signifying no change in his physical ability to perform masculinity. Matthew further asserts his masculinity by stating that he will continue to play rugby until he decides otherwise, irrespective of his breast cancer or others’ opinions; presenting himself as in
charge of his life by carrying on the behaviour into survivorship. This example again, illustrating the protective benefits of normalisation for men in the context of a breast cancer diagnosis.

Like Matthew, Michael also placed great importance on maintaining normality through continuation of his long-established male hobby, specifically, playing for his local darts team:

“it was a way of keeping a certain level of normality in that I’m not gonna give anything up just cos I’ve got breast cancer (.) I’m not gonna give up my darts and I played a couple times when I was having me chemo... not quite the same... but I tried to keep (.) it was a way with my darts with me running the leagues of just saying I ain’t goin’ anywhere it’s not gonna beat me I’m still gonna play darts I’m still gonna run the darts leagues all my friends still play and we carry on as normal”

(Michael, lines 1732-1738)

Michael discussed how he employed a number of normalisation techniques in coping with the psychosocial aspects of the breast cancer episode, including continuing to play darts and maintaining his long-standing role as the darts league secretary, both central components of his pre-illness male identity; the continuance of which serving to protect his masculinity and reduce disruption in his social life. Relating back to Knafl and Deatrick’s (1986) thinking (see
Chapter 7, p.198), Michael’s normalisation here provides further support for all four of the elements they identified, particularly the latter two – minimising the social consequences of the breast cancer episode by continuing with the regular social practice of playing darts with his friends; and also by still engaging in the management of the darts league, demonstrating normalcy to others, with nothing having changed from their perspective, despite Michael’s changed health status. Furthermore, Michael’s refusal to give up and/or be beaten by his breast cancer reflects a combative rhetoric (see Bush, 2002) that was common across the men’s accounts, implying that he has to fight to maintain normality and to retain the appearance of normality to others. While this could be interpreted as an assertion of his masculinity, it is worth noting here that fighting talk is not exclusive to men with breast cancer, nor the illness itself; with evidence of people using this linguistic style in experiential accounts of other chronic conditions (e.g. Hall, Rubin, Dougall, Hungin & Neely, 2005).

Nevertheless, by presenting himself as on the offensive and carrying on with life regardless of his breast cancer, Michael defends against the threats to his masculinity and social self.

Maintaining normality then in the context of breast cancer in men is shown here to have real protective potential for men defending themselves against related life disruption and masculinity threat. What all of the above examples show, whether in reference to maintaining normality in their personal, work or social lives, is how the men engineered breast cancer to live with them and fit with their lives, rather than living with breast cancer and being consumed by it, and/or losing their sense of self. This is discussed further in Chapter 8 where a ‘reconsidered and reconfigured’ masculinity is explored relative to the dynamism of normality and masculinity in the context of breast cancer.
7.3 Downward comparisons – breast cancer as worse for others: “…things could be worse…” (Ken, lines 1089-1090)

This subtheme considers how the men generally articulated a breast cancer diagnosis as being worse for others, especially women, implicating breast cancer as an assault on femininity rather than masculinity and its effects as less meaningful for men; simultaneously protecting and asserting their maleness by downplaying breast cancer’s potential to disrupt the male life course.

In giving their accounts, the men frequently compared their experiences of breast cancer to those of other patient-survivors, and/or other occurrences of illness and events in life with the capacity to influence lifeworld- identity- and self-meanings. According to Social Comparison Theory (see Festinger, 1954), in order to self-evaluate and establish both their social and personal worth, humans actively compare themselves to others in one of two ways; upwardly, which involves comparing themselves to people they consider to be more superior, so as to motivate themselves to be better, or downwardly; that is when a person compares them self with others they perceive as being worse-off, in order to feel better about their own circumstances. Though the men exhibited evidence of making both upward and downward comparisons relative to their breast cancer experiences – both of which are shown to have strengths and weaknesses (Corcoran, Crusius & Mussweiler, 2011) – by and large, downward comparisons presented more frequently across the men’s accounts; this supporting previous research (e.g. Cross & Madson, 1997) which has shown men when making evaluations are more likely to engage in downward comparisons in order to strengthen their sense of self.

Viewed as fundamentally defensive, downward comparisons are a process of self-enhancement intended to bolster self-esteem that is commonly identified in people adjusting to life-threatening and chronic illnesses, including cancer (Taylor, 1983). The concept of
adjustment to breast cancer using downward comparisons is not new, with evidence of both women (e.g. Krippendorff, 1998) and men (see Chapter 3) previously employing these evaluations as a method of self-protection against the illness threat; and also, against the perceived threat of relative emasculation, in the case of affected men. The men’s accounts revealed multiple examples of them looking for opportunities to self-enhance by way of downplaying other people and situations; the types of downward comparisons the men made varying between their individual accounts. However, three specific evaluations were consistently performed: comparisons to women with breast cancer, to other men – both with and without breast cancer – and to other illness events.

Downward comparisons to women with breast cancer presented as the most common type of comparison drawn by the men. As discussed in Chapter 3, research (e.g. Sime, 2012; Halls, 2013) has previously shown men to posit breast cancer as worse for women, which can have both positive and negative consequences for men; negative in that it downplays breast cancer in men, serving to further marginalise MEBs; but positive insofar as the comparison serves to protect and uphold their masculinity by presenting men as less affected by breast cancer than women, and thus, they appear better-off. When downwardly comparing to women with breast cancer, the men primarily focused on the embodied experience, articulating the physical effects of breast cancer to affront femininity and female embodiment in various ways; from losing feminine characteristics, e.g. through loss of hair and their breast(s), affecting the appearance and functionality of their breast(s), to impinging on their physical attractiveness and sexual attractiveness, as these excerpts from Paul and Maurice’s accounts serve to exemplify:
“Female breasts are part of a woman’s body image they’re part of the way that she presents herself to the world and part of if you like a confidence mechanism and... yeah its (.) if you think about it breasts a’ one of the defining characteristics of women... they’re very very definitely attached to female sexuality because they’re part of a shape of a woman they’re part of if you like the sexual allure of a woman”

(Paul, lines 1456-1458, 1461-1462, 1464-1465)

“it’s completely different from a man gettin’ breast cancer the women ‘aving it isn’t it...she’s gonna lose ‘er ‘air she’s gonna ‘ave a scar she’s gonna lose the feminine part of ‘er isn’t she y’know doesn’t bother me but it bothers women... there’s no comparison to ‘ow a woman feels I feel for women y’know dreadful... I’d o’ thought god ‘elp me if I’d a been a woman”

(Maurice, lines 519-520, 522-524, 532-533, 1900, 1903)

As femininity and masculinity are socially constructed and understood to oppose one another, by articulating breasts to be a defining female characteristic and “very definitely attached to female sexuality”, confidence and attractiveness, this in turn implies they are unconnected
with masculinity. Therefore, the threat of breast cancer to female embodiment and identity presents as far greater than it does to men’s, positioning women as worse-off than men, thus protecting affected men. To say there is “no comparison” between the effects of breast cancer on women and men both strengthens the men’s sense of masculinity and marginalises them at the same time. Despite reinforcing machismo, denying the impact on men potentially places them at the periphery of optimal care and support, if they are perceived as needing less attention; indicating the use of downward comparisons by men with breast cancer to have both advantageous and detrimental potential.

Regarding Maurice’s visual representation, when asked how the image made him feel, he replied: “I’d o’ thought god ‘elp me if I’d a been a woman... what woman wants t’ look like that?” (lines 1903, 1906); this demonstrating how he self-evaluates his altered embodiment against his belief that the embodied effects of breast cancer are more meaningful for women than for him as a man. Further, Maurice also explained how he purposefully had this photograph taken to enable him to show interested persons what his post-breast cancer body looks like, without having to undress; another protective practice, creating defensive distance between the visual representation of his body and his physical self.

As Paul and Maurice focused on the detrimental effects of breast cancer on women’s sexuality and body image perceptions in order to lessen the perceived impact on men and preserve their masculinity, Andy also protectively articulated the embodied experience to be worse for women:
“it’s a massive thing for a woman cos it’s part of her sexuality where as a man it’s not the same although it’s a terrible illness but i’ lose a breast for a woman must be (.) awful... it’s part o’ their sexuality that they’re losing isn’t it and at this day and age it’s all about what you look like and your figure and that impacts on women whereas a man (.) for me personally it’s not bothered me losing ma breast... if it was a testicle I’d be devastated”

(Andy, lines 112-114, 118-121, 123)

In trying to explain the way breast cancer affects women’s sexuality differently to men’s, Andy equates the loss of a female breast to a man losing a testicle, protecting his masculinity by positioning a man losing his breast as meaningless and non-comparable to losing a male sex organ. What this also signifies is a cognitive disconnection in Andy between non-male parts of his body and his sexual self; though whether this is a conscious protective practice is unknown.

Relatedly, Jim also discussed the impact of breast cancer on sexuality, and considered it sexually preferable that he developed the illness rather than his wife:

“I’m glad that I got it rather than the wife because she can cope with my um extent of mutilation if you like probably better than I could with hers”

(Jim, lines 332-333)

Jim’s comment gives further insight into men’s meaning-making about breasts and sexuality, implying that him having breast cancer is less detrimental to his sexual relationship, not only because he disassociates his breasts with his sexual self, but more so because of the importance he attaches to his wife’s physical appearance; suggesting he is less affected by changes to his own body than he would be by changes to his wife’s, and so regards himself as
better-off. This protective strategy of articulating the breast cancer experience as harder for those ‘looking on’ rather than the affected individual was also expressed by Ed: “there’s nothing they can do t’ take the pain or anxiety away it’s down to you and that’s really difficult for them” (lines 148-149). Again, this comment infers that others are more adversely affected by his breast cancer than he is and implies some degree of personal control and independence; all of which serve to preserve his masculinity.

As well as downwardly comparing to the physical effects of breast cancer on women, the men also made downward comparisons with regard to the emotional impact too; articulating the psychological implications of the illness to also be greater for women than men, as Roy discussed:

“from a psychological point of view it’s a damn sight worse (.) errrm for me self for us men t’ get cancer breast cancer it’s a threat to our lives but it’s not a threat to us y’know our hair falls out anyway I mean look at me it’s gone hah I’ve never used those [puts hands on breasts] for anything hah so yeah it’s unimportant I’ve got a scar there now well I had a bunch o’ those anyway so it’s just one more”

(Roy, lines 188-193)

Roy articulating breast cancer as “a threat to our lives but not to us” was a sentiment shared by many of the men, who while not wanting to take away from the severity of the illness in men were keen to protect against the perception that breast cancer affronts masculinity; hence them actively comparing with women and articulating the illness to affront psychological femininity: “there must be less emotional issues for a man” (Howard, line 92). In justifying this claim, the men gave various reasons why they perceive the emotional experience of breast cancer to be worse for women, including the greater meaning women attach to their breasts
and mastectomy accordingly: “women have a bigger problem with it because of their femininity…rather than a man where it’s just an operation” (Douglas, lines 440-443); and the potential to hinder women adhering to societal expectations and performing femininity: “men expect women to have breasts…they’re expected to be able to feed their babies breast milk” (Walter, lines 225, 227). Again, as with the physical comparisons, by turning attentions to the psychological difficulties with which women contend this distracts from the threat facing men, working to preserve their masculinity.

In addition to making downward comparisons to women, the men also compared themselves to other men whom they perceived to be worse-off than themselves. Paradoxically, a number of the men articulated themselves to be archetypal but not average, believing that they were superior to other men, especially others diagnosed with breast cancer; like Douglas, who described himself as the exception to the rule:

“it didn’t bother me in the slightest but I would say well in fact I know that I’m exceptional rather than the rule… the very fact that some men seek advice somebody to talk to… I would never have considered that at any stage because to me it wasn’t something I needed to talk to anybody about”

(Douglas, lines 231-232, 493-500)

Douglas considers himself superior to men who engage in help-seeking, possibly because he perceives this to have emasculating potential, given that seeking help is incongruent with masculine norms (Addis & Mahalik, 2003); this comparison doubly protecting his masculinity by showing him to adhere to socialised male norms and confirming his dominant position relative to other men.
The following quotes from Derek and Paul also exemplify how men articulated themselves as superior to and better-off than other men:

“I don’t think most men are hah like me anyway I suppose without sort of blowing my own trumpet I’ve been through a lot since I was 16 errrm I enjoy conflict”

(Derek, lines 713-715)

“I’m not actually part of the usual demographic for male breast cancer I’m younger I’m not morbidly obese I (. ) I don’t really fit the bill”

(Paul, lines 841-843)

By differentiating themselves from the usual male breast cancer demographic, and asserting themselves superior insofar as being experienced in dealing with adversity, and advantaged by their younger age and good health besides the breast cancer, the men present themselves as better-off than other men; indicating hegemony, thus protecting their masculinity. Equally, by comparing himself to men he considers to be subordinate, Roy further exemplifies how the men performed protective-assertive masculinity through the use of downward comparisons:

“for me it is not an assault on my manhood as such... okay for the guys that are sort of a little flaky and go errr well y’know erm I can’t wear pink cos that’ll turn me into a girl kinda thing you know (. ) these guys it must be sort of a disaster for them”

(Roy, lines 162-162)

Roy works to protect his masculinity here in two ways; firstly, by explicitly stating that breast cancer does not affront his manhood; and secondly by inferring that breast cancer is only a concern for men who struggle with their masculinity: “not all are like me” (line 1124) – this
comment articulating himself to have greater self-assurance in his male identity than others, and in turn, asserting his superior male status.

Perhaps unsurprisingly given the typically older age of breast cancer onset in men, for many, the breast cancer diagnosis was neither their first nor their only encounter with life-threatening illness, enabling the men to draw comparisons with other first-hand illness experiences. In protecting and asserting their masculinity, several of the men appraised breast cancer as less threatening than other illnesses they had experienced, including for instance myocardial infarction, temporary paralysis and other cancers. As Maurice explained, having previously undergone what he described as “an apprenticeship of disaster” (line 296) concerning his health, he had already become desensitised to the occurrence of serious illness when diagnosed with breast cancer:

“I ‘ad all the trauma of me heart problems and so you’re a bit blasè when something else happens you’re kinda like wellllll nothin’ can be worse than ‘avin’ an ‘eart attack and collapsin’ in the street then it’s you’ve got breast cancer well y’know urrrhh I’ve gone through all this before”

(Maurice, lines 300-304)

Derek also expressed a similarly stoic response to developing breast cancer based on his illness history:

“I’ve faced death more than once so my attitude to it is what’s gonna happens gonna happen and that’s how I view it whether or not other people view it like that I don’t know I doubt it”

(Derek, lines 717-719)
Both excerpts serve to demonstrate how the men protectively draw on their survival of previous illness experiences to downgrade the impact of breast cancer on their lifeworlds and identities. Further, the men also assert their masculinity here, showing themselves to be impervious to the threat of serious illness having previously endured, overcome and survived multiple life-threatening events, indicating strength of character.

As well as appraising breast cancer as less threatening than other illnesses, some men also downplayed their diagnosis by positing cancer type to be a lesser concern than cancer itself: “cancer is the first thing and the breast is secondary” (Douglas, lines 91-92); almost implying that the location of the cancer was irrelevant, despite repeatedly articulating breast cancer to be problematic for men’s masculinity. Relatedly – and also to the first subtheme – the men also sought to downplay their breast cancer by suggesting “it’s the same as any other cancer” (Graham, line 76) or “just another cancer” (Ewan, line 252); drawing comparisons in order to normalise the diagnosis, and thus protect their masculinity.

In some instances, the men also made hypothetical downward comparisons between breast cancer and other illnesses, particularly in relation to male-only illnesses; like Ed who posited a breast cancer diagnosis as preferable for men in comparison to being diagnosed with a male-specific cancer:
“for all the cancers t’ get for a bloke probably breast cancer’s the easiest one to cope with... y’know if you’ve got testicular or prostate cancer or anythin’ like that that’s more for a bloke more difficult I think... it never affected me psychologically y’know it’s no great shakes so given the choice if somebody said d’ya want breast cancer or d’ya want testicular cancer I’d personally go for breast cancer as a man... because I don’t think losing a breast is such a big deal for a man but y’know if y’ become impotent or whatever I think that’s a little bit psychological”

(Ed, lines 85-90, 98-100, 102-106)

As Andy’s earlier comment about potentially losing a testicle showed, by comparing to male-only reproductive cancers which pose a direct threat to the appearance and functioning of male sex organs, Ed significantly reduces the perceived threat of breast cancer to masculinity; this preserving his male identity and further, illustrating how meanings of masculinity are entwined with those attached to masculine embodiment and sex.

Further, some men also drew comparisons to non-illness-related adversities too; like Maurice, who explained how reading tragedy-themed poetry – paradoxically not something usually associated with masculinity – helped him to cope by realising that his circumstances could be worse:
‘ow I’ve cope is I read a lot of poetry….it’s the first thing that gets y’ head round a disaster your health trauma love relationships because there’s some bugger somewhere’s already wrote about it an’ ‘ad a worse time than you y’know if you go into poetry you go oh that poor bugger”

(Maurice, lines 601, 603-605)

Posited as a protective practice in that Maurice feels secure in the knowledge that others are worse-off than himself, reading about others personal tragedies also serves to normalise adversity, making it appear less threatening and surmountable, bolstering his self-esteem. Robert on the other hand considered he was better-off than people who had never experienced, as he described it, “real problems”; protecting his masculinity by portraying himself as worldly-wise and prepared by experience to deal with adversities like breast cancer:
“I thought that just summed it up (.) some people just don’t have a care in the world y’know their biggest thing is whether a toad ‘ll get across the road that’s the most serious thing in their lives... some people will just sail through life with nothing going wrong (.) erm an’ I think actually I’m glad because I think sometimes in life it does you good to have a bit of a problem... you see another side a life... and actually I think it’s quite healthy to have an understanding of life”

(Robert, Int.2, lines 488-490, 493-494, 501-503, 541-542)

Robert’s comment implies that experiencing breast cancer provided him with a sense of perspective previously unknown to him, enabling him to develop a fuller understanding about his life and relative meaning-making. Hence, when comparing to persons who lack exposure to life’s adversities, Robert’s position presents as being advantageous, upholding his male hegemony. This, together with each of the abovementioned examples, showing the protective value of downward comparisons to men coping with breast cancer.
7.4 Resisting formal support while recognising its worth: “I can do this I don’t need any help” (Douglas, line 554)

This subtheme explores some of the men’s aversive attitudes towards engaging with formal support services, despite them recognising the value of such services, and how many disassociated themselves from persons accessing formal support; preferring to position themselves as support-providers rather than recipients, thus upholding a hegemonic standing.

Perhaps unsurprisingly, given that research has consistently shown men are disinclined to seek help (Courtenay, 2000; Galdas, Cheater & Marshall, 2005; Robertson, 2007), and especially for psychological issues (Oliver, Pearson, Coe & Gunnell, 2005; Liddon, Kingerlee & Barry, 2017), many men repeatedly articulated rejecting opportunities for support – formal or otherwise – demonstrating a preference for dealing with their breast cancer independently, rather than accepting help from others; be those professional, familial or fellow patient-survivors. Although previously posited as maladaptive behaviour and the principle health-related issue facing men in the UK (White, 2001), men avoiding help-seeking here in the context of breast cancer is interpreted as being an assertion of their masculinity in the form of a protective coping practice. In contrast with hegemonic masculine identity which typically reflects power, strength and stoicism in the event of adversity, help-seeking and the acceptance of help are socially constructed as unmasculine behaviours (McVittie, Cavers & Hepworth, 2005); hence, men who wish to adhere to hegemonic male ideals may disassociate themselves from these behaviours to protect against masculinity threat, as appeared to be the case with many of the men interviewed.

While most of the men acknowledged the potential benefits of engaging with support services, e.g. Walter: “to share my experiences with them and they share there’s wi me y’know... it would perhaps build y’ confidence up” (lines 306, 313), and expressed concern
about the lack of support available for men, e.g. Peter: “there isn’t err any real kind of support for men it just doesn’t exist” (lines 531-532); paradoxically, of the men who were offered opportunities for support, many of them declined any involvement insofar as accepting help, e.g. Graham: “I didn’t feel the need” (line 786). As Chapple, Ziebland and McPherson (2004) noted, men reject support for a multitude of reasons, including a fear of appearing weak and lacking masculinity, and have repeatedly been shown to put themselves at-risk rather than transgress social expectations for men and help-seeking; concerned that in seeking support they may be associated with undesirable emasculate traits, like vulnerability and dependency (Galdas, 2009). According to Courtenay (2000), health behaviours provide men with an opportunity to exhibit ‘real’ masculinity to themselves and others, and to situate themselves in a masculine arena by ‘doing’ masculinity as it is socially prescribed, e.g. a man who appears unconcerned about his health, as independent and not needing support, thus asserts his male identity (Galdas, 2009). This may explain why many of the men were keen to highlight their infrequency in healthcare settings prior to the breast cancer episode, except for encounters of serious illness, e.g. Michael: “I hadn’t been t’ the doctors for ten years” (line 15); the significance of the ‘absent man’ in clinical settings having previously been discussed by researchers exploring men’s health (see O’Dowd & Jewell, 1998).

In line with Courtenay’s (2000) supposition, the men in giving their breast cancer accounts made explicit links between their health/illness behaviours and male identities, particularly when discussing support and help-seeking. The men’s reasons for declining support were varied, and though they recognised it might be important for others – especially women – several said that, for them, they “didn’t feel it was necessary” (Clive, line 788); suggesting that these men viewed themselves as emotionally superior and better able to self-manage the diagnosis than others, thus asserting their masculinity. Some said they completely overlooked
utilising support services, claiming: “I’ve never thought about it’” (Neil, line 858), “I didn’t really know that they were out there” (Andy, line 652); while others were admittedly deterred from engaging with support due to the typical female gendering of breast cancer support facilities: “all the support networks are setup for women” (Peter, line 522), questioning the relevance of the support on offer to men: “what are they going to give me?” (Graham, line 838). Further, others said that seeking support was simply not in their character, like Darren and Jason:

“No that’s not me, do you know what I mean, I don’t do things like that”

(Darren, line 1192)

“I never really thought I needed support t’ be honest not the sort o’ person t’ go to therapy or want to sit down and talk about things”

(Jason, lines 900-902)

By suggesting that they are not the kind of people (men) to seek support, Darren and Jason present themselves to have a traditional male attitude towards help-seeking and importantly differentiate themselves from those who engage in such behaviour; again, working to protect and assert their masculinity. Likewise, Bill’s reasons for rejecting support also demonstrate how typical masculine beliefs may have influenced their behaviour:

“I have never felt the need to discuss what I have got with somebody else (...) its personal isn’t it... you have got to deal with it, people can’t help you really”

(Bill, line 451)

Bill articulating that his breast cancer is personal implies that it is private, demonstrating incongruency with public disclosure. It could also be interpreted as him taking ownership and control of his illness – internalised coping mechanisms which further reflect the men’s shared
belief that only they can help themselves to manage and make sense of their breast cancer.

Men’s adherence to the masculine norms of self-reliance and emotional control has previously been shown in men with prostate cancer (Burns & Mahalik, 2006), where they were associated with greater psychological distress; a finding that is consistent with and supported by this research, which found men who avoided seeking external support and/or attempted to cope with their breast cancer independently typically appeared less well-adjusted to the illness event than the men who engaged with support services. Further, they also showed a tendency to experience greater perceived masculinity threat, despite making concerted efforts to avoid this. Therefore, it could be argued that while men with breast cancer believe strict adherence to male norms will protect their masculinity, this could in fact increase their vulnerability, and thus potentially further threaten their male identity in addition to their health.

Though a common male survival strategy, Masculine Dysfunction Strain Theory (Levant, 1996) explains how rigid conformity to traditional notions of masculinity can lead to poorer health behaviours and negative health outcomes; the process of protecting against any event that threatens to violate male norms, e.g. breast cancer, potentially causing additional strain in their lives. Evidence of this is exemplified by Paul, who declined professional support for his breast cancer until he experienced what he described as “the wobble” – essentially, a period of health anxiety caused by discrepancies between his expectations about breast cancer and the reality of his situation, which profoundly impacted on his sense of self:
“I’ve always looked on myself as being pretty imperturbable (. ) pretty kind of impervious to any kind of thing that’s coming at me (. ) the wobble when it comes down to it it’s a case of (. ) yes it’s normal (. ) but it’s not the way I wanted to do it (. ) I didn’t wanna have that wobble... see that’s me that’s how I see myself (. ) impervious armoured and difficult to get at...it is a case of when you’re vulnerable you want to camouflage that vulnerability”

(Paul, lines 934-937 1746, 1750-1751)

Image 25, Impervious, armoured and difficult to get at, Paul (lines 1742/1743)

Having always viewed himself to have stereotypically characteristic traits of a ‘real’ man, i.e. imperturbable and impervious to threat, Paul struggled to identify with feelings of vulnerability and having to seek support, declaring “I’m not proud of that” (line 929); this comment illustrating how deviation from traditional male norms prompted relative masculinity strain and a sense of shame in seeking support. Paul’s desire to ‘camouflage’ his vulnerability further indicates a fear of being perceived to be weakened by his breast cancer diagnosis and feeling compelled to protect his male status accordingly; his armour a visual representation of him defending himself against the relative masculinity threat. Interestingly, Paul himself acknowledges that experiencing distress relative to a breast cancer diagnosis and needing support for that is ‘normal’, only not for him, as ideally this is not how he would have responded; his meaning-making here reflecting self-disappointment, and also the self-belief that he perceived himself as stronger than he presented to be when faced with adversity. The
incongruence between his perceived and actual illness response here threatening his sense of self as a hegemonic male.

What is interesting with regards to the men rejecting support is that many realised the potential for them to experience poorer adjustment and poorer health outcomes resultantly: “there’s nothing macho about being dead” (Paul, line 1614), yet continued to prioritise protecting their masculinity above all else. For example, Douglas described how he avoided seeking support, his behaviour seemingly influenced by his traditional male attitude: “that’s just me I’m independent me err like I can do this I don’t need any help” (line 554); however, he later advised against other men rejecting support as he did: “…don’t do as I do do as I say…talk to people” (lines 832, 840), still standing by his behaviour, whilst recognising that it potentially put him at-risk. This could also explain his decision to become a patient volunteer with a breast cancer charity post-illness, a role through which he vicariously receives support whilst importantly presenting himself as a provider rather than recipient of care; benefitting from the supportive interactions while simultaneously maintaining his masculinity.

Of the proportion of men that did access breast cancer support services, wanting to help others presented as the men’s primary motivation for engaging with support. Like Douglas, the majority of men showed themselves to be more comfortable giving support rather than receiving it, especially if they thought they were helping other men: “it’s a bit of therapy for me but…it’s more that I don’t want others [men] thinking they’re the only one” (Andy, lines 679, 681); presumably because they viewed helping others – particularly men – as a way of asserting their manliness and hierarchical social positioning. However, with reference to Andy’s comment, in supporting other men, the men also helped themselves; reducing feelings of not belonging and unusualness, helping to normalise breast cancer in men, and in turn protecting the masculinity of MEBs.
Though many of the men rejected support altogether, despite initially dismissing the idea, some men later decided to engage with breast cancer support services. More often than not, these men claimed to change their decision purely to satisfy others – usually their spouses – and not because they personally felt they needed support; again, demonstrating how the men worked to protect their masculinity, as Glenn’s comment illustrates:

“I didn’t wanna go... I was quite reluctant at the time erm stop mithering me y’know just get on with your own life I’m alright kinda thing cos I’m not really a sorta person that (.) it’s quite weird for me t’ be talkin’ to you about all this but erm sitting in a group with strangers all wi’ cancer didn’t appeal t’ me at all thought it’d be the most miserable possible experience I’d ever feel but I couldn’t’ve been more wrong”

(Glenn, lines 449-454)

Having primarily attended a support group – he claims – to pacify his wife concerns, Glenn articulated an initial reluctance and scepticism towards seeking support, reflecting a traditional male attitude of wanting to get on with life and avoid difficult discussions; thus, he was surprised to discover the positive difference accessing support made to his breast cancer experience, describing it as “the doorway to life again” (line 1385). Glenn admitted that seeking support opposed what he thought was the best way of dealing with his breast cancer and claimed that had it not been for his wife’s intervention, he would never have sought emotional support, despite recognising issues himself: “I was a totally different person” (line
This again showing how the desire to protect and live up to dominant masculine ideals in the context of breast cancer outweighs men’s other concerns, regardless of their importance, and potentially puts men at-risk of poorer health outcomes.

Not all men were as positive though about their decision to engage with breast cancer support services, believing that it was in fact detrimental to their coping: “it depresses you” (Geoff, line 532). To protect themselves against transference from others, some men decided to discontinue seeking support. Some men also rejected informal opportunities for support from breast cancer counterparts, purposefully avoiding interacting with others in clinical settings, as Michael did:

“I was waitin’ for my appointment an’ there was two ladies with breast cancer chattin’ and they were so negative I had to move away and sit in a different area cos () I can’t think like that () I’m not gonna think like that and I didn’t... clearly I didn’t say anything to them but I couldn’t cope with the negativity”

(Michael, lines 376-380)

While Michael admitting that he “couldn’t cope” is incongruent with traditional masculinity, his decision to remove himself from the negative situation is protective, showing him to be in control; which could also be interpreted as him asserting his masculinity. Further, his refusal to think negatively and/or to succumb to the emotional effects of breast cancer also reflects an assertive masculinity; illustrating independent thinking and nonconformity to typical patient (female) behaviour.

7.5 Proving male credentials: “I’m a bit of a man’s man” (Glenn, line 699)

This final subtheme exhibits the ways and means by which the men articulated themselves as being archetypically male despite breast cancer’s incongruence with traditional masculinity,
making reference to hobbies, interests, beliefs and behaviours that (stereotypically) are socially assumed as ‘being’ male, in order to cement their male identity.

Vandello and Bosson (2013) claim that the threat and anxiety men experience when their gender status is challenged results from the way in which society views femininity and masculinity; as unlike womanhood, which is typically regarded as a natural and stable progression, manhood is posited as something men earn, and is maintained through performing “publicly verifiable actions” (Vandello & Bosson, 2013, p.101). This is thought to encourage men to engage in a variety of risky, maladaptive and avoidant behaviours; thus, the precariousness of masculinity (Vandello, Bosson, Cohen, Burnaford & Weaver, 2008) can have important implications for men across various domains – including men’s health – and especially for those under situations of gender-threat, as in the case of men with breast cancer (see Chapter 6).

Research (e.g. Cheryan, Cameron, Katagiri & Monin, 2015) has previously shown threatened men to deploy specific gendered strategies when their male identity is questioned, including disavowing female preferences, and claiming more stereotypical masculine attributes, so as to enforce their male prowess. Such masculine overcompensation (see Willer, Rogalin, Conlon & Wojnowicz, 2013) was commonly expressed across the men’s breast cancer accounts; the men frequently making references to interests, beliefs and behaviours which, stereotypically, are socially assumed to reflect male gender. In likening themselves to archetypes of manliness, the men work to preserve their masculinity; protecting their male gender identity by asserting themselves as conformists to traditional male norms and practices, irrespective of masculinity’s incongruence with breast cancer’s typically female identity.

By and large, the most common way the men sought to evidence their male credentials was through making references to engaging in stereotypically male gendered sports and activities,
including football, fishing, golf and shooting; all of which were visually represented by the
men (among other sports) and are socially synonymous with ‘being’ male:

*Image 27*, Old Trafford, Geoff
(Int.2, lines 13/14)

*Image 28*, Fishing, Michael (lines 1768/1769)

*Image 29*, Pink Golfers, Ed (lines 1479/1489)

*Image 30*, Uther & Gun, Paul (lines 2033/2034).

Articulating them as preferred recreational activities both pre- and post- breast cancer, and
also as established coping mechanisms previously used to deal with life’s adversities, the men
discussed the meanings and value they attach to engaging in their male hobbies; and all the
more so during the breast cancer episode, when their sense of self and masculinity is
threatened. For example, Geoff recalled how he went to watch a football match on the same
day he was formally diagnosed with breast cancer:

“We’d got tickets to go to Manchester United to watch them play that evening and I
got my results that morning... I told my friend as we were going up cos he didn’t
know... I still really wanted to go... it’s a fantastic atmosphere if you go to
Manchester United its uplifting and for an hour an’ a half I forgot about what was
happening ...it was a very strange day a mixture of elation and excitement fear and
trepidation... I still remember the score though hah it was two nil and Rooney scored”

(Geoff, Int.2, lines 16-18, 51-53, 96-98, 100)

Although implicit, Geoff describes how watching Manchester United served as a convenient
distraction following receiving the confirmed diagnosis that same day, indicating him to have
exercised avoidant coping in making the decision to still go; not least because he articulates
Old Trafford to be an uplifting environment offering him escapism, if only temporarily, for
the length of the football match. Towards the end of the excerpt, Geoff purposefully diverts
talk away from emotions by mentioning the football result and refers specifically to the male
sporting icon Rooney: demonstrating his use of available male resources to protect and assert
his masculinity.

Contrastingly to Geoff, Paul and Michael were more explicit in the ways that they
acknowledged their male hobbies to operate as protective defence mechanisms:
“that is one of my coping strategies... TWO of them actually shooting and Uther...
Uther is a horse who’s had a lot of health problems... he’s actually had about as much surgery as I have and (.) him and the shooting for me it’s control... me in control of the situation... when I shoot I pride myself on hitting what I am aiming at and having to be totally controlled under those circumstances”

(Paul, lines 2036-2038, 2047-2048, 2050-2053)

“it’s a hobby of mine but fishing for me was a coping mechanism... I would go and sit there in the freezing cold pretending t’ be fishing not catching nothing cos it’s far too cold but it gave me time to think about everything (.) an’ I needed that time sometimes just to sit there and think about where I was with the breast cancer what was comin’ in the future y’know what the possibilities were rather than sit and let things build up so fishin’ was an escape if you know what I mean”

(Michael, lines 1770-1799)

As previous research has shown (e.g. Canham, 2009), loss of control correlates with increased suffering and masculinity threat in men; thus, Paul continuing to perform hobbies which afford him a sense of control and mastery throughout the breast cancer episode protects him against emasculation, and psychological maladjustment to the illness. Similarly, for Michael, maintaining fishing as a hobby served as a protective smokescreen, providing him with a manly reason and purpose to spend periods of time alone and be with his thoughts; enabling him to process his meaning-making about the illness event in a controlled way, on his terms. Though individual in how they assert and protect their masculinities, both examples indicate how the men highlighting their engagement in male gendered hobbies and interests works to preserve their male identity.
As well as articulating themselves to have a penchant for male gendered leisure activities, as earlier mentioned (see 7.1), the men also looked to validate their masculinity by drawing attention to their working lives. The men spoke at length about their work selves and how breast cancer affected their professional roles and identities; some denying it to have any impact whatsoever, continuing to work throughout the entirety of the illness episode, only taking time out for scheduled treatment: “I had the operation and I was back at work within (.) less than a fortnight actually” (Derek, lines 156-157). Some even took on an increased workload while undergoing treatment, possibly using work as an avoidant coping tool to protect themselves against the illness threat, and/or correspondingly, performing extra duties to assert their masculinity:

“I was working full time I had quite a demanding job and actually took on additional responsibility whilst I was having treatment”

(Graham, lines 8-9)

A number of the men said they had – or previously held, if retired – high-status working roles within well-established, successful organisations. Example positions included: chief executive, company director, lead advisor, officer and chairman, all of which indicated the men to have power, dominance, and authority over others in the workplace – especially other men, since the majority worked in male-dominated professions, including those in lower ranking jobs, e.g. builder, bus driver. Those who had working roles which earned them social kudos, particularly from other men, were especially keen to talk about their role and its relationship with hegemonic masculinity, like Michael who was a high-ranking police officer:
“...the national perception of police officers er is it’s a macho role an’ I should’ve ‘ad the mickey taken outta me for havin’ breast cancer really but I didn’t...just before the diagnosis I’d got the dream job that I’d always wanted which is fraud squad in probably the most respected fraud squad in the country or the world even... I still got massive pride in what I do”


Michael highlighting that his working role is socially perceived as ‘macho’ serves to validate his manhood, indicating that his male identity was already socially well-established, suggesting that this is perhaps why he avoided being ridiculed; something which he implies men diagnosed with breast cancer expect to happen. Further, drawing attention to how highly regarded and respected his line of work is both nationally and globally indicates a sense of hierarchy and self-importance, plus a sense of self-actualisation in articulating the pride he has in realising his “dream job”; all of which are representative of his hegemony, protecting his self-identity.

Interestingly, several of the men explicitly acknowledged breast cancer’s potential to impact on men’s machismo, but in trying to protect their male identity, most denied any personal impact; projecting the relative masculinity threat to be a real concern for others but not for themselves, as Paul does here, again drawing on male work roles and resources to support his claim:
“I’ve never really had to turn around and say LOOK AT ME I’M MACHO because I am built like a brick outhouse because I’ve done all of these incredibly macho things (.) I’ve done a lot of things that a lot of other blokes are jealous of... the army officer I’ve done the pilot thing the freefall parachuting thing mountaineering I’m a horseman done all of that and I still got it (.) so to me it’s not a case of oh that must mean you’re incredibly effeminate (.) not really no... it’s less challenging for men like me who’ve done macho things (.) I know it sounds a bit weird but maybe it’s being secure in y’ masculinity”

(Paul, lines 851-853, 855-858, 865-867)

Paul overemphasising his masculine credentials contradicts his implicit claim that he feels no need to justify his masculinity, which he considers to speak for itself, given his masculine appearance and typically male accomplishments. However, in presenting himself as hyper-masculine, such overprotection of his masculinity arguably reflects insecurity rather than self-assurance in his male identity. Paul’s suggestion that other men are jealous of his male achievements also demonstrates his competitiveness – another stereotypically male trait (Moxon, 2015), and further assertion of his masculinity; as is his comment “it’s less challenging for men like me who’ve done macho things” which implies he is more manly than other men, and therefore is less threatened by the breast cancer diagnosis.

Several of the men in attesting their male credentials looked to protect and assert their masculinity by distinguishing themselves from non-hegemonic males and practices. As previous research has shown (e.g. Glick, Gangl, Gibb, Klumpner & Weinberg, 2007), in defending against masculinity threat, men will target groups/subgroups stereotyped as having specific traits they wish to deny in themselves, so as to affirm their higher male status. Thus, subordinate males, e.g. non-heterosexual MEBs, may find themselves at risk from men whose
masculinity is under threat, e.g. heterosexual MEBs, as this excerpt from Roy’s account exemplifies:

Roy:  ...yes it’s breast cancer it’s a disease I’m a normal heterosexual man I’m a granddad... I’m fit healthy I climb mountains sail boats I’m up to all sorts of things bit of a man’s man to be honest and I got breast cancer (.) there’s nothing wrong with me (.) now unfortunately two of my mates they are both gay which doesn’t really help the cause

Int.  Why?

Roy:  well that they’re gay there’s something wrong with them y’know they’re not normal (.) so this sort of underlines well there’s gotta be something wrong with you as a man to have breast cancer y’know sort of a bit feminine (.)

(Roy, lines 505-529)

Roy appears to benchmark his masculinity against not only his ability to perform male-typical behaviours and roles, but also his discordancy with subordinated forms of masculinity; protecting his male credentials again by implying that he is more of a man than others (see Anderson, 2009). Roy’s comment that being gay “doesn’t really help the cause” implies that gay men developing breast cancer further threatens the masculinity of men diagnosed with the disease, given embedded social assumptions about homosexuality’s association with effeminacy (Cocks, 2007); hence his desire to disassociate himself from gay men, and to present himself as a male gender traditionalist (Anderson, 2009).

The men distinguishing themselves from non-hegemonic males closely relates to earlier discussions about them making downward comparisons (7.3); however, here, the primary purpose is not to bolster their ego, rather to emphasise their adherence to traditional
masculinity by creating distance between themselves and atypical presentations of male identity. In doing so, the men protect themselves against flawed assumptions about breast cancer in men representing effeminacy or hypo-masculinity, demonstrating alpha males to be equally vulnerable to the illness threat despite their machismo, thus normalising the diagnosis: “I’m bit of a man’s man to be honest and I got breast cancer.”

Beyond making references to male-gendered hobbies and work roles, distancing themselves from unconventional manifestations of masculinity, and presenting themselves as personally impervious to masculinity threat; further, the men commonly articulated themselves to be competitive and goal-oriented in asserting their male selves, again purposefully showing themselves to conform to masculine stereotypes (Cuddy, Crotty, Chong & Norton, 2010). Many of the men posited breast cancer as a challenge requiring them to engage in a contest of physical and mental endurance, which although difficult and trying at times, they almost relished: “it becomes sort of a game really hah... I’ve quite enjoyed the challenge” (Robert, Int.1, lines 625-626). This meaning-making may have protective potential for men, as to view breast cancer as a game infers that it is something the gameplayer (patients and survivors) can win and be victorious over, presenting it as an opportunity for competition and success; both of which ‘real’ men are said to strive for (Verdonk et al, 2010).

Further, not only did the men posit breast cancer itself as a challenge, they also discussed setting themselves various challenges as a way of coping with and defending against the threat of breast cancer. More often than not, these challenges were tests of physical strength and ability, but which unexpectedly trialled the men’s mental stamina too; so, not only serving to assert their masculinity, but protecting it through a process of self-affirmation, sustaining the integrity of their male self (Steele, 1988). Proving to others, and also to
themselves, that they could still perform masculinity post-diagnosis as they did pre-breast cancer was important to the men, as Geoff exemplified:

“I’d got these targets that I set myself and wanted to do when I was better and that’s at Tongariro crossing in New Zealand... it’s as difficult a walk as a I would’ve done when I was fit before the breast cancer... and I felt if I could get fit enough to do that I’d feel I was back to normal”

Geoff (Int.2, lines 365-366)

Similarly, Glenn also set himself the physical challenge of completing a demanding bike ride on entering recovery:

“I did a bike ride for charity which was sixty odd miles and I’d just come outta hospital...and yeah that bike ride Manchester to Blackpool was kind of wow y’know you are still alive and capable of achieving things”

Glenn (lines 1425-1428, 1452-1454)
For both men, setting and completing these challenges signified to themselves and others that they were still fit and able in spite of the breast cancer episode, confirming their sense of capability, while also providing them with a sense that they were still able to achieve goals they set post-illness. In demonstrating sustained physical prowess – a key marker of masculinity – the men attest their male credentials, showing themselves to be unaffected, at least physically, by the breast cancer experience; and thus, protect their male identities.

7.6 Chapter summary

This second analysis chapter has looked at how and why men adopt a protected and asserted masculinity, as they look to preserve and maintain their male identity across the breast cancer trajectory. As the corresponding subthemes serve to illustrate, recognising breast cancer’s potential to compromise their masculinity, the men perform multiple protective behaviours and make various efforts to assert their manliness in defending themselves against the perceived masculinity threat. The protective-assertive behaviours identified include, attempting to normalise breast cancer, especially in men; downplaying and downwardly comparing their diagnosis – particularly to breast cancer in women; finding it hard to accept support; causally attributing their breast cancer to male behaviours; and searching for ways to prove male credentials. As discussed, performing these protective-assertive practices – from the men’s perspective – works to preserve the men’s sense of self as a man at a time when their masculinity is under threat. However, in reality, these behaviours are arguably maladaptive (Ghaderi, 2015); potentially serving to increase the risk of threat to the health and masculinity of men with breast cancer.

In Chapter 8, the final masculinity process identified – reconsidered and reconfigured masculinity – becomes the focus of interest, where the men’s paradoxical transitioning from a resistive and protective masculinity to a relaxed, and arguably diluted masculinity, is
discussed. With reference to the schematic representation presented in Chapter 6, this last analysis chapter looks at how differently the men perform masculinity and how men’s attitudes change as they progress towards breast cancer recovery and life beyond the illness.
Chapter 8 – Analysis – Superordinate Theme Three: Reconsidered and reconfigured masculinity

In the previous two chapters (6 & 7), two masculinity themes have already been outlined and discussed: ‘threatened and exposed’ and ‘protected and asserted’; specifically, what these illustrate and represent with regard to how the men construct masculinity in navigating their way through the breast cancer experience, and also the point in time across the course of illness when these masculinities are performed, how and why. Continuing with this linear-like presentation of the study findings, whilst recognising that the reality is not linear or stage-like but rather more plastic and dynamic, this chapter considers the last of the three identified masculinities to feature in the schematic representation (see Chapter 6, p.137); reconsidered and reconfigured masculinity. As with the previous two chapters, this chapter begins by introducing the masculinity theme, considering how it is conceptualised both independently from, and as part of the schematic representation; thinking about it in view of the preceding masculinities and how the men adjust to adopt a reconsidered and reconfigured masculinity, typically post-treatment, as they rehabilitate and advance towards being ‘in recovery’ from breast cancer. In contrast to the first two superordinate themes which capture how masculinity is protected and used as a resource, ironically, this last theme demonstrates how the breast cancer episode seemingly affords men freedom from the constraints of hegemonic masculinity; showing them to relax stereotypical male attitudes and behaviours as they reconsider and reconfigure their understandings about breast cancer and ‘being’ male, liberating them accordingly.

This final masculinity is reflected upon by the men as the illness episode comes to an end, and they begin to make sense of their lives post-diagnosis and treatment; preparing for and constructing, or rather reconstructing, life beyond the malady. Referenced by a number of the
men interviewed, the status of being ‘in recovery’ has a particular poignancy, as although the term ‘recovery’ implies a return from illness to health and back to normality, this is indefinite; with recurrence of cancer possible. Hence why the use of terms like ‘survivor’, ‘cured’ and ‘recovered’ are contested by some members of the breast cancer community (Khan, Harrison, Rose, Ward & Evans, 2011); including some of the men interviewed for this study. Nevertheless, irrespective of how the men labelled life beyond breast cancer, and/or whether they perceived their recovery from breast cancer to be unending, almost all of the men were able to rethink their biographies and self-conceptualisations post-treatment, despite the disruptive event (Bury, 1982). As mentioned earlier in Chapter 2 (2.2.4), Halls (2013) claims that Bury’s (1982) concept of chronic illness as biographical disruption is less applicable to men (than women) and breast cancer, due to their marginal position and the lack of resources made available to men to help guide them in rethinking their lives post-illness. However, based on this study’s findings, it is argued that despite their underprivileged circumstances – and perhaps in some instances, because of this – men living with breast cancer are able to successfully reconsider their identities and masculinities whilst maintaining a sense of self, as this final theme demonstrates.

The experience of breast cancer for the men interviewed, as the first two masculinity themes illustrate (see Chapters 6 & 7), unequivocally presented as a critical situation and life course disruption in the way that Bury (1982) describes the advent of chronic illness. For example, interrupting taken-for-granted assumptions, explanatory frameworks, and common-sense boundaries already cognitively stored by the men, and which they had previously been socialised to draw upon when making sense of men’s health, masculinity and breast cancer; resulting in cognitive and socio-emotional conflicts for men who receive a breast cancer diagnosis. However, as Williams (2000) noted, Bury’s (1982) thinking regarding disruptions
of taken-for-granted assumptions is somewhat reductive, failing to account for a host of other possibilities as to why chronic illness may take centre-stage in peoples’ biographies. This is shown in several of the men’s accounts, with many of them articulating breast cancer as a “biographical continuity” (Williams, 2000, p.52) across their life course; the breast cancer episode, for some – perhaps inevitable given the typically older age of affected men – one of many illness-related events they had endured (see Chapter 7–7.3), either directly themselves, or vicariously through significant others, some of whom also had a history of breast cancer.

Nevertheless, Bury (1982) acknowledges that the meaning of chronic illness is complex; time- and context-dependent, viewed in terms of both its practical consequences (for the self and significant others) and symbolic significance (Williams, 2000). Again, this corresponds with the men’s accounts and their meaning-making of the breast cancer experience which they appraise practically, in view of the disruptive effects breast cancer has on their everyday lives – personally, professionally and socio-economically – and symbolically, insofar as the connotations of Western representations of breast cancer for men (Quincey et al., 2016); affecting how the men view themselves, and how they perceive others to view them following the breast cancer diagnosis. This meaning-making, as discussed and illustrated in Chapters 6 and 7, typically takes places across the first two masculinity themes identified; the men mobilising contextually available masculine resources appropriate for masculine construction changes situationally (Messerschmidt, 2000), e.g. in the advent of breast cancer.

The changes men (and women) experience relative to breast cancer occurring are generally assumed unwelcome and unpleasant; prejudged, from a common-sense point of view, as having negative connotations for affected individuals and their significant others. However, experiencing breast cancer can also have positive connotations; serving as a catalyst for creating change (Strauss & Corbin, 1988), empowering individuals to challenge embedded
assumptions – both illness and non-illness specific – providing fresh urgency and perspective, and exposing new possibilities for exploration. ‘Benefit finding’ – i.e. seeking to find positive aspects in, and to grow and learn from life’s adversities (Tennen & Affleck, 2002) – in the context of a life-threatening illness has been explored with various clinical populations, including breast cancer in women (see Sears, Stanton & Danoff-Burg, 2003, Tomich & Helgeson, 2004) and other male reproductive cancers (e.g. prostate cancer, Pascoe & Edvardsson, 2016); with findings suggesting that benefit finding may be associated with improved psychosocial and behavioural adjustment to serious illness (Littlewood, Vanable, Carey & Blair, 2008). To date, research exploring benefit finding among men diagnosed with breast cancer (e.g. Pituskin et al., 2007; Ackroyd, 2016) is limited. However, the current study findings show benefit finding is common among men who embrace a reconsidered-reconfigured masculinity; demonstrating how men ‘do’ gender to influence their illness cognitions and their recovery from breast cancer.

Reflecting on the breast cancer experience and their changed selves accordingly (physically and psychologically) as they near the end of their treatment, and contemplate their future selves and life ahead, the men appraise their pre-breast cancer selves and lifeworlds; re-evaluating values and priorities, the men that they are and were, compared to the men they desire to be. The lived breast cancer experience, and all that coincides with it for men (psycho-socially -sexually and -emotionally), causes them to revise their worldviews on and meaning-making of multiple facets within their lives; including health and illness – especially breast cancer – and ‘being’ male, engendering the emergence of a reconsidered masculinity, illustrative of the men rethinking their male identities, bodily and self-conceptually (Corbin & Strauss, 1987). This reconfigured sense of identity that the men exhibit presents either after having successfully undergone treatment for their breast cancer, or alternatively, having
accepted that the disease cannot be adequately treated (cured). In either case, whatever the remaining length of lifespan perceived, following their breast cancer diagnosis, the men articulated a need to enjoy life better, and to become a better version of themselves, specifically, as it was recurrently expressed “better men”; the men critical of their pre-breast cancer social selves’ for multiple reasons, including for example prioritising work-life over home/family-life, and communicating (emotionally) with others, and themselves, ineffectively.

Five subthemes were identified within the data which serve to support and illustrate the concept of a reconsidered and reconfigured masculinity:

**Table 11. Subthemes for The Superordinate Theme Three**

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**8.1 Life beyond breast cancer: “as bad as an illness like breast cancer is there’s a future” (Ed, line 1357)**

This first subtheme explores the men’s desire to illustrate that their lives are greater than and extend beyond the breast cancer episode, also the *Carpe Diem* attitude expressed by many ‘in recovery’, as they consciously endeavour to enjoy life better post-illness.
Despite the seriousness attached to receiving a breast cancer diagnosis – clinically and socially – the men were keen to highlight that life, for them, did not end upon getting the confirmed diagnosis; in fact, quite the opposite for the majority of the men interviewed, as Peter explained: “It’s not the end of the world it can be very positive” (line, 1252). In their accounts, many of the men declared previously preconceiving breast cancer, and indeed any cancer diagnosis, as tantamount to a death sentence, more likely than not to result in loss of life, and to reduce a person’s quality of life prior to their eventual mortality. However, following their own breast cancer diagnosis, owing to a shift in perspective, these preconceptions changed; as Ken and Robert both explained using the same metaphoric expression “light at the end of the tunnel”. This indicating their belief that life beyond breast cancer is possible and that breast cancer is not necessarily synonymous with death, as they had prior assumed:

“I think that was kind of the big lesson for me that y’know that it wasn’t a death warrant... there’s light at the end of the tunnel”
(Ken, lines 89, 1070)

![Image 34, Light at the end of the tunnel, Robert (Int.2, lines 315/316)](image)

When discussing the above image and its meaning, Robert interprets the light in the distance as representative of his future life beyond breast cancer; a marker for where illness ends and...
life resumes. However, he questions whether it is possible to “ever reach the light” (Int.2, line 342), i.e. to return to life as it was pre-breast cancer – this illustrated by the way the road to the light cannot be seen. Relatedly, Robert commented “once you’ve had cancer you always live with cancer” (Int.2, lines 359-360); this is akin to the concept of cancer as a constant, as earlier discussed in Chapter 6 (see 6.5). Nevertheless, he maintained: “that’s where we’re aiming” (Int.2, line 332). Thus, despite perceiving breast cancer as being omnipresent in his life going forward, he still believed in a future life, and remained hopeful that life could be restored, with some reconfiguration. The belief in a life after breast cancer was typically shared by all of the men; even those with secondary cancers, for whom recovery was unlikely: “be positive you’re okay you’re not gonna die tomorrow” (Jonathon, lines 1337-1338). The following comment from Ed further evidences future-thinking among the men, re-emphasising the shared belief that life goes on, irrespective of a breast cancer diagnosis:

“as bad as an illness like breast cancer is there’s a future... illnesses don’t finish things necessarily... being ill doesn’t end y’ life or stop y’ doing things”

(Ed, lines 1357-1359, 1607-1608)

Like Ed, most men chose to articulate breast cancer as enabling rather than disabling, and to position themselves as superior rather than inferior to the illness episode, possibly as a way of protecting their masculinity (see Chapter 7); refusing to relinquish control of their future life to the disease, with many vowing to enjoy life more than ever post-illness: “post breast cancer it’s about enjoying yourself” (Ed, line 1315).

Life was very much viewed by the men as a fluid concept and something that is continually progressing; a process that is incapable of being halted by anyone or anything, including the
occurrence of a life-threatening illness like breast cancer. The men articulated this shared perspective in varying ways, offering both visual and verbal expositions of this viewpoint. For instance, Glenn’s visual representation entitled ‘Life moves on’ depicts moving traffic beside a newly opened metro line; a development local to where he resides which progressed during the course of his breast cancer episode:

“that was built pretty much while I was ill or it started when I was going through this process an’ it just struck me that it doesn’t matter what’s going on in my life life moves on and you can choose t’ sort of get off the train if you want or stay on it”

(Glenn, lines 2058-2061)

Paying attention to his spatial context, Glenn uses this tangible, and arguably masculine, example to explain what is very much an intangible concept, i.e. that his lifeworld is continually transforming; irrespective of his ill-health, and regardless of whether he plays an active or passive role in these on-going transformations. Interestingly, Glenn positions this as a matter of choice; as something that he controls rather than the breast cancer – or indeed any other external influence – discussing how he actively takes greater ownership of his life, and responsibility for his own happiness and well-being, post-illness. Thus, affirming himself as renewed following the breast cancer experience, illustrating his changed cognitions and
behaviours using several examples, including re-evaluating the company he keeps (see 8.5) and pursuing new, more fulfilling hobbies.

Most men seemed to share Glenn’s belief that “life doesn’t wait for you” (line 1565) and expressed living with a stronger sense of urgency and desire to realise life’s possibilities post-diagnosis than they had prior to having breast cancer; many vowing to live life to the fullest, making conscious efforts to do more of what they enjoy once treatment(s) had ceased – a common finding among many diagnosed with chronic illnesses (Robinson, 2017). For some of the men, this change in perspective brought about changes in their professional selves too, causing them to reconsider the meaning of their working lives and professional identities; with most of the men, who were in work at the time of their diagnosis, choosing to reduce their working hours, or opting to take early retirement once in recovery. Articulating this change, Jason and Neil both explained how work, once a key component of their existential selves, has less centrality in their lives post-illness:

“it sort of made me realise that I’ve got a life outside of work... there’s more to life than just work”

(Jason, lines 1045; 1321)

“before it ‘appened it was all work orientated... it’s totally different now I don’t care about being at work... my main interests now are my home ma family what’s going on around me... that’s more important now than it’s ever been”

(Neil, lines 1107-1112)

The occurrence of breast cancer in the men’s lives seemingly made them more in touch with the here-and-now than they were before the illness event, with many men consciously adopting a Carpe Diem attitude post-diagnosis and treatment. The men exhibited this in a
range of ways, examples included; embracing new opportunities (see 8.2); being less cautious with money when previously they would have been careful about expenditures; and no longer putting off ‘bucket-list’ endeavours. The following excerpt from Jason’s account serves to illustrate this newly emerged attitude shared by many of the men as they progressed towards breast cancer recovery:

“So I saw this bike it’s one o’ the biggest ones that Harley do so I decided to swap the bike I had for that one... it’s like make a change now because you don’t know what’s around the corner... yeah just go for it sod the expense put it on the never-never”

(Jason, lines 1486-1487;1491;1515)

The ‘Harley’ very much dominates the scene photographed and reflects how Jason’s ‘bike features heavily in his life after breast cancer. He recalled how he was temporarily unable to ride his motorcycle post-mastectomy due to the physicality required, and how he missed riding being a part of his life; presenting this as a symbol of his recovery. Interestingly, Jason articulated his love for motorcycling as being greater than ever post-treatment; possibly as a reaction to this temporary omission he experienced, causing him to realise the enjoyment it provides him with, and how much he values it as part of his male identity. The emphasis he places on size and stature when comparing this bike to his previous one, coupled with the
nonchalance he expressed regarding the cost of this expensive upgrade, is interpreted as an exertion of his masculinity but also his changed attitude to life beyond breast cancer; fuelled by his uncertainty about the future, yet also represents his future-thinking.

Although the image is primarily intended to represent the Harley, the background scene is also noteworthy here, since the image was taken by Jason while on holiday soon after finishing his breast cancer treatment; holidays – especially motorcycle holidays – occurring more frequently post-diagnosis, and central to Jason (and others) finding enjoyment in life beyond the breast cancer episode. Several of the men mentioned holidaying, or wanting to, more often after their illness experience. For instance, Clive told of how he fulfilled his ambition to go on a cruise ship holiday after being treated for breast cancer, keen to point out: “you are still able to enjoy the niceties of life” (line 1645); a sentiment echoed by almost all of the men interviewed, and also providing an indication of the otherwise privileged circumstances of the study sample, as not all men or cancer recoverees would be able to afford such extravagances.

8.2 Embracing new opportunities and life experiences: “…it wouldn’t’ve happened if I hadn’t got breast cancer…” (Tom, line 1924)

This subtheme exemplifies possibilities and outcomes that the men’s breast cancer experiences gave rise to, re-enabling and emancipating them in spite of the restrictions imposed on them by the chronic illness.

The men’s accounts provide numerous and varied examples of how the breast cancer episode afforded them new and often unexpected opportunities and experiences. When talking about new opportunities that presented alongside or subsequent to having breast cancer, by and large the men recounted positive experiences, especially in early survivorship (as previous
research with cancer patients has shown, see Stanton, Rowland & Ganz, 2015); keen to position the illness as life-enriching and -enhancing in spite of the drawbacks earlier discussed in Chapters 6 and 7, with many describing themselves as “lucky” and “blessed” to have been exposed to these new opportunities, irrespective of the concurrent threat to their life.

For instance, Peter explained that whilst holidaying with his wife, specifically intended to help him recuperate following a difficult cycle of chemotherapy, he encountered a kingfisher for the first time, which he simultaneously managed to capture on camera. This he articulates as quite a feat, with kingfishers being fairly rare – akin to breast cancer in men – and difficult to photograph, expressing his joy at seeing the bird and the sense of achievement he gained in capturing the image. Discussing the photograph, Peter points out that the opportunity to experience this chance event may never have presented had he not had breast cancer: “I wouldn’t have been there I wouldn’t’ve had a reason to go” (lines 1502-1503).
“I managed to get three shots off and got it...I’d never seen one before (.) it was a once in a lifetime thing I’ve not seen one since either AND I managed to take a picture of it... again it’s strange without the cancer it probably wouldn’t’ve happened”

(Peter, lines 1491-1503)

This first-time experience, for Peter, is especially meaningful because it occurred during a period of recuperation from breast cancer treatment, and also reflects the pride he takes in his photography; a hobby which he first engaged with whilst undergoing treatment, offering him a new identity as a photographer and restoring his sense of self-worth by enabling him to realise he is “still something beyond the cancer” (line 1527). Peter told of how he showcased his kingfisher photograph (among others) at a local exhibition – another first for him – selling the canvas pictured for money:

“that somebody wanted to pay for my image made me feel fantastic that y’know even though like there’s this cancer in the background and I was going through it all I was still able to do something and for it to be appreciated... the whole thing made me feel very positive... without the cancer I don’t think I would’ve done it I don’t think I’d ’ave been as interested in photography”

(Peter, lines 1508-1510, 1516-1518)
These related yet separate experiences brought about by the breast cancer episode seemingly served to revitalise Peter’s masculinity and sense of self in multiple ways. For instance, not only did he observe the relatively rare bird, he was also able to capture the encounter on camera, enabling him to later profit from the experience financially as well as intrinsically; kudos and a sense of his own capabilities deriving from the former, and from the latter, a sense of purpose and mastery – both traditional male virtues.

Unlike Peter’s examples which are interlinked, Michael discusses two unrelated events that occurred following his breast cancer diagnosis; the first, relating to his long-term sporting interest, darts. For Michael, playing darts is a central component of his male identity, arguably even more so post- than pre-illness, transforming from a social hobby sustained over many years with male friends, into a platform from which he developed an annual community-based fundraising event in support of local breast cancer services (see 8.4); this advocacy initiative propelled by Michael playing darts at the Alexandra Palace, an unlikely opportunity that presented for him whilst recuperating after treatment:
Michael explains how his day at the Alexandra Palace “was the beginning of coming through the other side” (line 1581) and learning to enjoy life again. He also considers the experience the starting-point of his involvement with breast cancer advocacy and activism which post-treatment became, and remains, an integral part of his lifeworld, affording him a sense of purpose, responsibility, importance and accomplishment: “if it wasn’t for that particular day the publicity the promotion of what I’ve been doing since wouldn’t have taken place” (lines 1573-1574)

Like the breast cancer event itself, the subsequent occurrence of this new experience was also meaningful and impactful for Michael, fulfilling a long-term ambition to practice his favourite hobby at the world-famous arena; offering a sense of good fortune in spite of the illness
experience, and later leading him to develop a new identity as a breast cancer advocate, reconfiguring both self- and social-perceptions of the man he is.

The second example Michael gave relates to an opportunity that arose for him, where he was asked to address an audience at a Cancer Research UK staff training day, solely on the basis of him having breast cancer and as a beneficiary of cancer research. Michael explained how he had previously convened with staffs at Cancer Research UK’s headquarters incidentally as part of his professional life, though only at superficial levels until his breast cancer diagnosis; his ‘survivor’ status affording him greater insight into the organisation: “had what happened to me hadn’t happened I would never have seen the inside workings of Cancer Research UK” (lines 1610-1612). The experience of delivering talks to staffs of varying levels – from “canteen lady to top professors” (line 1000) – empowered Michael, as he commanded people’s attention and respect, and recognised the influential role he has as a man living with breast cancer; a position typically perceived to be subordinate (see Chapter 3, and Quincey et al., 2016), yet in this context is esteemed and revered. Thus, restoring Michael’s dominant masculine identity, which faltered at points in the early to mid-stages of illness, as he struggled to accept and adjust to role changes and losses professionally:

“...you walk in and you get silence you get all the people listening to you and it’s that powerful effect that you have over people discussing what you’ve been through”

(Michael, lines 1620-1621)

This exclusive opportunity to link-up with Cancer Research UK reconfigured Michael’s masculinity in a different way to the Alexandra Palace experience; affording him status, power and recognition similar to that which he realised – and self-congratulated – in his role as a long-standing police officer, indicating his male identity to have evolved, rather than devolved, in line with the breast cancer experience.
Similarly, Howard’s breast cancer experience also led to him becoming a spokesman; representing not only the male minority within the breast cancer community, but also patient-survivors with deafness, working in conjunction with the charity Breast Cancer Care:

“I have given talks to groups about breast care and what to look for to check for breast cancer (. ) the groups are mainly of deaf people... it was a new experience for me to give talks which I found enjoyable”

(Howard, lines 108-110; 175)

As a man living with profound deafness and a history of breast cancer, Howard articulated pride in being able to represent these typically separate, yet for him, converging identities; how he embraced the opportunity to raise the profiles of both male and deaf members of the UK breast cancer population, and how empowering this was for him, gaining recognition on all fronts in spite of the many challenges associated with his multiple minority identities.

In addition to finding benefit in the new experience of delivering talks relating to their breast cancer experiences, several of the men spoke at length about another unique opportunity experiencing breast cancer afforded them – the chance to take part in *The Show*: an annual fundraising fashion-show event hosted by Breast Cancer Care which sees predominantly female patient-survivors become catwalk models for an evening, dressed in designer wears and accompanied on-stage by famous, usually female, celebrities. The popular event is profitable for both the charity and service-users alike, raising funds to maintain valued non-clinical patient resources, whilst simultaneously designed to bolster the ‘models’ self-esteem and encourage positive self-conceptions post-diagnosis. Six of the men interviewed recounted participating in *The Show*; a meaningful experience held in high regard by all of these men, but which they could never have known without their breast cancer diagnosis.
The positive effects of experiencing *The Show* are evidenced in this image of Tom walking the catwalk; his open and upright posture (something that many breast cancer ‘survivors’ never fully achieve again post-mastectomy) projecting confidence, energy and vitality, despite disclosing that he felt unwell at the event due to undergoing chemotherapy the day before; hence him feeling “defiant” here, determined to enjoy the experience despite his ill-health:

“that’s me on the catwalk in front of about a thousand people... I really enjoyed it cos I do love attention hah (.) no one told me to put me arms up like that but I did hah... I love that picture ‘cos I’m so defiant there... jus’ makes y’ feel good (.) it wouldn’t’ve happened if I hadn’t got breast cancer”

(Tom, lines 1237-1240; 1276; 1924)

*Image 39*, The Show, Tom (lines 1237/1238)

Modelling on a catwalk was a first-time and unexpected experience for all of these men, going beyond their norms and comfort zones, and admittedly was not something that many of them would have entertained pre-diagnosis, all typically gendering catwalk modelling, like breast cancer as ‘female’:
“there’s no way I would’ve done this catwalk thing [before] I mean I’m a scruff really hah I hate dressing up... but y’know I don’t mind looking a prat for a bit hah hah BUT I would never have done that before”

(Geoff, lines 1140-1143; 1159)

Though Geoff equating looking good with “looking like a prat” arguably reasserts traditional masculinity here, his comment also illustrates his new-found willingness to embrace opportunities that come his way since his breast cancer diagnosis, and his now nonchalant outlook on practices that would previously have irked him, i.e. dressing formally; demonstrating a reconsidered self and approach to life experiences.

Furthermore, participating in The Show reminded the men of their minority position within the breast cancer community, with most recounting how they were either the sole man or one of only two male models at their respective shows. However, this did not deter them from participating:

“there’s not such a plentiful supply of men... but you go there get kitted out meet people... get totally pampered... it’s a tremendous experience really”

(Ken, lines 463; 467; 470; 545)

Rather, being one of few men involved in the event fostered a sense of importance and pride; the men viewing themselves as representatives for breast cancer in men, revelling in raising awareness and the purpose derived from this opportunity. Participating in The Show, quite literally, enabled these men to enter the spotlight, gaining a sense of inclusion belonging and indebtedness to the breast cancer collective; making for an unforgettable life-affirming experience, where breast cancer was formally acknowledged as part of their reconfigured
male identity. Men finding benefit specifically in relation to engaging with breast cancer activism and advocacy is discussed further in section 8.4.

### 8.3 A renewed identity, becoming a changed/better man: “I’m a finer man of a person now that I was before” (Geoff, Int.1, line 477)

This subtheme explores the perception, shared by several of the men and/or their significant others, that experiencing breast cancer has improved them as men and that they identify with a changed, better version of themselves post-illness, both socially and emotionally.

Not only did (most of) the men find the breast cancer episode to be an enriching and life-affirming experience, many agreed that having breast cancer changed the men with which they self-identified pre-illness, resulting in a reconfigured male identity; often, this being a self-proclaimed improved version of themselves. Across the accounts, the men gave various reasons, shared and different, as to why they considered themselves to be better men following their breast cancer experiences. Reasons ranged from recognising positive changes to their temperament and personality and their treatment of others relatedly, and also their cognitions and behavioural practices; especially in relation to their mental and physical health. Identifying changes in their own temperament and personality post-illness was especially common among the men, with several of them referring to their improved character:

“I think character wise it’s improved me... I’m free-er more open... I’m more relaxed”

(Roy, lines 1151-1155)
Roy goes on to discuss how the breast cancer experience has liberated him insofar as he no longer “sweats the small stuff” (line 1157), i.e. stresses about trivial matters as he did prior to his diagnosis, resulting in an improved self-concept for Roy. Similarly, Darren also believed that the breast cancer experience had given rise to a less stressed and more relaxed version of himself:

“...that’s the difference it’s made (.) now I don’t stress so much”

(Darren, lines 1511-1512)

Darren explains how he transformed from being “a right grumpy git” (line, 1256) who frequently shouted when conversing with others into a “chilled man” post-diagnosis and treatment, now taking daily stressors, which previously he would have over invested in, at face value; a personal change he considers to be beneficial for him and his family.

Likewise, Geoff also recognised that he too had newly adopted what he considered to be an improved attitude to life after experiencing breast cancer, suggesting that he was a “finer man of a person now than before” (Int.1, line 477). Geoff considered himself to have a calmer, more casual disposition post-illness compared to the former self with which he identified; a change he seemingly regarded as preferable:

“I used to be a bit stroppy at times before whereas now... I don’t get so angry as I did y’know...there’s more of a live let live sort of attitude... generally I’m more tolerant of things”

(Geoff, Int.1, lines 479-481, 489-490, 1134)

Many of the men used negative adjectives like “angry” and “grumpy” to describe their pre-breast cancer selves; words which are, stereotypically speaking, more readily associated with ‘being’ male; reflecting a sterner, dominant persona, illustrative of their prior hegemony
which the men were keen to portray. However, most men were equally as keen, if not more so, to demonstrate the personal developments they underwent across the breast cancer trajectory; all seemingly positive about their cognitive, emotional and behavioural transformations:

“maybe you’ll come out the other end a slightly better person ‘cos I think that I am a kinder man now than I used to be I mean I can be quite sharp and abrasive... but I think I’ve mellowed a little... I think how I feel about myself has changed for the positive”

(Peter, lines 1253-1256, 1260)

Again, like Geoff, Peter’s choice of words to describe his pre-breast cancer self, such as “sharp” and “abrasive”, are stereotypically reflective of a hegemonic male’s character, akin to stridence and assertiveness (Connell, 1995). Peter’s comment infers that although he still has these intrinsic traits, he perceives these as flaws to his character, preferring to think of himself as a “better”, “kinder” man now, attributing this solely to his breast cancer experience.

Several of the men believed that they had improved tolerance and were humbler having experienced breast cancer:

“makes y’ a better person... in ‘ow you deal wi’ people you’re a little bit more considerate yer a bit more understanding... I’m very considerate an’ supportive an’ a better person now... it does make y’ a better person”

(Ed, lines 1257, 1259-1260, 1262, 1266)
“I think I’ve become a more tolerant person... I think I’ve become less arrogant... I’ve become a much better person in the sense of I’m prepared to listen to people more perhaps... there’s a certain passivity which has come into the way in which I’m looking at things as well so that’s an interesting change”

(Jonathon, lines 1112-1114)

Since being diagnosed with breast cancer, Jonathon recognises a “passivity” in how he responds to life’s happenings; quite the opposite to his pre-breast cancer self, whom he describes as “arrogant”, and a man that liked to be in control, indicating a relaxing of his hegemonic masculinity. Jonathon articulated this as an “interesting change”, implying he is somewhat intrigued yet bemused by this difference he acknowledges in himself, whilst simultaneously suggesting this is a change for the better, despite his perplexity. Further, he recognises that these unexpected self-changes are not only positive for him but for others too, admitting that he shows more respect for others and their views post-breast cancer.

Those who claimed the breast cancer experience had made them a better person/man were asked to explain this proclamation. Initially, the majority found it difficult to express why they believed they were better men post-diagnosis, which may explain a lack of supportive, visual data. Nevertheless, most were able to eventually explain their meaning; many simply viewed their new, less stressed and more relaxed selves with greater positivity. Others evaluated their post-breast cancer selves in terms of positive changes to their personal and social selves, including being more considerate and supportive of others, and more appreciative of elemental facets than their pre-breast cancer selves; the latter, another common finding in cancer/chronic illness literature (Brodsky, 1999; Unruh, Smith & Scammell, 2000; Arman & Backman, 2007). Several men discussed finding value in things they had perhaps previously overlooked or underestimated in terms of their perceived
importance, and believed that recognising this made them better men; many demonstrating
greater environmental awareness and a fresh appreciation for plants, flowers, wildlife and
landscapes post-illness:

“Being ill has made me appreciate
life and how things grow... at one-
time y’d a took that for granted...
now you just appreciate about nature
about life... I would never ’ve ’ad
that... the only time I’d ’ave gone
outside would a been to a beer
garden... this symbolises what I
never appreciated before... we all
walk through the garden but we don’t
smell the roses...being ill... it makes
y’ stop in yo

ur tracks a bit and
appreciate just what is around you
what gives you joy”

(Ed, lines 791-792, 1545-1557,
1565-1566)

“I was a hunting shooting fishing man... I’d think that’d be nice in my cooking pot...
I’d see a pheasant and he might have pretty colours... but now I’m looking at the
pretty colours”

(Roy, lines 1059-1063)
Articulating his point, Ed explained how he had grown the flourishing palm tree (Image 40) from a small plant in his back garden; a space where at one-time growing conditions were poor, prior to the ground being re-developed. Ed discussed with a sense of pride and achievement taking joy in seeing the plant thrive, describing it as “therapeutic or something” (line 1549) to watch it prosper in spite of the once difficult ground conditions. The same could also be said for Ed himself, who exhibits personal growth through the adversity of his breast cancer diagnosis; recognising and appreciating the critical importance of environment and place to his existential self and life, only when his future existence is threatened. Alternatively, Roy, keen to portray himself at least behaviourally as hegemonically masculine, articulates his pre-breast cancer self as a specist; regarding animals as subordinate to humans, despite acknowledging their qualities. However, he identified changes in his cognitions and behaviours post-breast cancer, recognising that he views things differently, and is more “emotionally effected” (line 1075) by life’s simplicities than he was prior to having breast cancer. What both examples demonstrate is that in embracing a reconsidered and reconfigured masculinity, the men simultaneously show a relaxing of hegemonic masculinity; Ed switching from drinking beer in a garden to nurturing plants, while Roy goes from shooting game to admiring its beauty; both of which can be regarded as self-enhancing behaviours, consistent with them becoming ‘better’ men.

In addition to the men themselves recognising that their breast cancer experiences had enhanced their cognitions, attitudes, behaviours and identities, in some cases, these changes were also acknowledged by others. For instance, Andy discussed how his step-brother had remarked upon positive changes to his temperament and improved social skills post-diagnosis:
“My step brother said that it ‘ad changed me… in a better sense…in the way I spoke to ‘im and treated him things like that... but I thought I’m just treating y’ exactly the same... am not treatin’ y’ any different what y’on about... he says I like y’ lot more now because you speak t’ me prop’ly and the cancers changed ye”

(Andy, lines 553-556, 558, 560-561)

Initially, Andy was reluctant to accept that having breast cancer had changed how he interacts with his step-brother. However, later on in his account, he acknowledges that his pre-breast cancer self was perhaps more reticent than the man he now self-identifies with post-illness: “I think am more confident and open about things” (line 933). Andy’s self-observation here somewhat contradicts his earlier comment about being “exactly the same” as he was before, as he admits that he expresses himself and connects with others differently post-illness, believing that he is more self-assured since his breast cancer experience.

The example from Andy’s account evidences this concept of changing for the better in view of the direct feedback he received from his step-brother. However, in most cases, the men commented on their perceptions of others viewing them as changed and/or better men:

“...people’s perception of me has changed for the better I would’ve thought because of what I do for the charity… I think it’s changed me and it’s changed people’s perceptions of me locally…”

(Michael, lines 876-877, 1679-1681).

Reconciling self-enhancement and self-verification (see Swann et al, 1989), Michael firmly believed that people in his local community view him differently since having breast cancer, and largely attributes this to him setting up a fundraiser whilst in recovery (as mentioned in 8.2), through which he continues to raise large sums of money for his local oncology unit.
Though he struggled initially to come to terms with the changes that having breast cancer brought to his professional life, Michael draws great strength from the event he now hosts annually, and the public support both he and the occasion receive locally:

“there's actually people that've messaged me on Facebook who've said I've just been for my latest round of chemotherapy and your money has done this and is making a difference”

(Michael, lines 764-766)

Knowing that his fundraising efforts are held in such high regard and that the money raised is directly benefitting members of his local community reinforces Michael’s sense of achievement and feeling of gratification; something formerly provided to him pre-illness by his professional role, reincarnated post-illness in his self-developed role as a breast cancer advocate and local benefactor, a role many of the men embraced (see 8.4). As in Andy’s case, this direct feedback that Michael receives from others reinforces the concept that the men’s breast cancer experiences typically brought about positive changes for themselves and others, often resulting in a reconsidered masculine self-concept post-illness.

8.4 Engaging with breast cancer activism and advocacy: “me having breast cancer as one person ‘as made thousands aware…” (Neil, lines 1311-1312)

This subtheme considers the ways and means by which the men have become involved with efforts to raise awareness of breast cancer in men and offered their support for those affected by breast cancer in light of their own experiences with the illness, and how this has enhanced their lives accordingly.
The men’s involvement with breast cancer activism and advocacy was considerable and varied (and possibly overrepresented because of the nature of the study sample); ranging from engaging with common and conventional practices often embraced by patient-survivors, such as participating in large-scale popularised charity-led events (see Images 41 & 42), to contributing to niche alternative and creative innovations specifically intended to raise awareness of breast cancer in men more widely, and to less typical audiences, i.e. beyond the breast cancer community. Most of the men interviewed identified with being a breast cancer activist/advocate, and several of the men were keen to present themselves as frontrunners in raising awareness of breast cancer in men (e.g. participating in The Show, see 8.2), highlighting the roles they have played in educating the public and health professionals about the illness in men, and improving patient practices and facilities since their diagnoses. In a way, this is also reminiscent of asserted masculinity too (see Chapter 7), with these men positioning themselves as leader, and others as beneficiaries.

*Image 41*, Relay for life, Maurice (lines1841/1842)
One example of an alternative method of engagement, provided by Tom, involved contributing personal items for the ‘Breathless Breastless Project’; a touring art exhibition showcasing thought-evoking words and imagery authored by those affected by breast cancer (women and men), representing their lived experiences of the illness. Tom explained how through writing his blog ‘One in 300’ – another creative outlet through which he communicates his breast cancer experiences – he connected with the exhibit developer, who invited him to take part. A short piece of prose provided by Tom briefly articulating his experience of hair loss whilst undergoing chemotherapy, accompanied by the hat he wore throughout having the treatment, was artistically interpreted in sculpture form and featured within the exhibition (Image 43).
Though the nondescript sculpture itself offers a degree of anonymity, at the same time, the use of Tom’s real name (blacked out here for ethical reasons), personal belongings and his ‘voice’ to create the piece exposes his identity, which is somewhat paradoxical. However, Tom explained how the partially revealing artwork has benefitted him in multiple ways, such as when presenting himself in an online context; taking a photograph of the sculpture to use as his profile picture, enabling him to reveal elements of his true self but in a protected way:

“I quite often use it if I go on a message board and things that’s often actually my avatar that... it was a really good exhibition somethin’... I’m proud to be involved in”

(Tom, lines 1841-1842, 1846-1847, 1851)
Tom’s sense of pride relative to his involvement in this project, which aimed to highlight some of the emotional challenges facing people affected by breast cancer, and to empower these individuals to share their emotional journeys, is evident in the way he talks about the exhibition and reflects on his contribution; what it represents, for him and others, and how far he considers he has come personally since his diagnosis and primary treatment. For Tom, the cap which he frequently wore to conceal his hair loss and ever-changing appearance during treatment and recovery remains to be a very personal and poignant item, yet he is willing to put the item on public display and bare his emotions for the benefit of others affected by breast cancer, which again is seemingly paradoxical, and uncharacteristically male. Though it could be argued that participating in the exhibition was a cathartic experience for Tom, as he commented: “the effects never wear off and are still in your mind” (Tom, lines 1862-1863), suggesting that he recognises the need to promote and facilitate emotional healing, and the potential benefits of doing so (see also 7.5).

Another example of innovative breast cancer activism, also provided by Tom, included writing and performing songs with lyrics about men and breast cancer; the intention being to better educate people about the illness and to promote breast cancer equality, as reflected in the lyric: “it’s as manly as it is girly” (see Image 44). The song titled ‘Never Mind Your Bollocks’, written by the band that Tom played with at the time of his diagnosis, was penned specifically to raise awareness of breast cancer in men; reminding people, especially men, of the benefits of self-examination and being bodily aware as opposed to only being aware of potential health threats to male-only areas of their bodies, e.g. the testes. The style of the song and also the accompanying artwork are explicitly masculine in their presentation, and very definitely oppose typical femininity and breast cancer imagery; though whether that was specifically the intention or unconscious is unknown:
Proud to serve as the muse for both the song and an innovative method for raising breast cancer awareness, Tom was keen to discuss the semantics behind the song’s development, and also what it meant to him personally to have the support of his bandmates, whom he articulates as fellow advocates for change, and collectively as an “equal opportunities band” (line 1915). His decision to include the above image is twofold: not only does it display the song’s lyrics which are breast health promotion themed, but it also incorporates the band’s album artwork, showing a man on his knees together with the album title ‘This Band is Sick’ a double entendre where sick [sic.] as a slang term means ‘good’ – in reference to the music – but also reflects the suboptimal health status of some of the band’s members, including Tom. Tom described the quirky track, which is publicly available and free to access online, as “just another way of it being out there makin’ people aware of male breast cancer” (line 1925-1926), somewhat downplaying the innovation despite its potential to have wide-reaching
implications. When asked whether raising awareness of breast cancer in men was important, Tom replied “definitely” (line 1943), affirming what is apparent throughout his account, that advocating for men and breast cancer is now firmly a part of his reconfigured identity and life.

Like Tom, several other men also engaged in less orthodox means – at least for men – of breast cancer activism and advocacy. For instance, Eammon featured as Mr October (Image 45) in an otherwise all-female ‘Calendar Girls’ style nearly-nude calendar, sold to raise funds for a local breast cancer charity:

*Image 45, Mr October, Eammon (lines 1440/1441)*
Self-admittedly disconcerted by his changed embodied appearance post-breast cancer, Eammon discussed his initial reluctance to model for the calendar and publicly expose his bare chest; something which he struggles to do in private in front of his partner, and even when alone. Nevertheless, he recognised the benefits of being the calendar’s male representative; of “stepping-up” and the potential to encourage others to do the same, believing that for men to “shy away” from such campaigns is problematic for men:

“I’d rather sort of tell people spread the word whereas a lot of men as far as I can see they do won’t do that... I want to get the word spread I think it is important... these men who sort of shy away from or are not prepared to sort of advertise the fact as I always say if you don’t do how are we going to progress”

(Eammon, lines 1616-1617, 1620, 2047-2048)

As in Tom’s case, Eammon posing shirtless also presents as paradoxical behaviour, but the distance and unreality he describes feeling when thinking about people seeing the calendar image versus his naked torso in-person – particularly his partner – affords him the self-confidence to share with others the physical effects of his breast cancer; raising awareness of the illness in men, perhaps even more so as the sole man among a female majority, whilst simultaneously representing the higher female-to-male ratio.

In addition to the different practices the men engaged with, the men’s reasons for becoming breast cancer activists, and for advocating for men especially, were also varied. Some felt duty-bound to raise the profile of breast cancer in men, while for others it was seemingly more of a personal crusade; a way of asserting themselves, by campaigning for social and political/policy change, and striving for gender equality in future breast cancer care and practices:
“I thought I had a duty of care effectively coming out of me and the fact that everyone I spoke to had no idea men could get breast cancer was ringing in my ears all the time I was really totally aware that right this ‘as gotta change we’ve gotta do something about this’”

(Ewan, lines 203-206)

Three of the men interviewed, including Ewan, were NHS staff at the time of their breast cancer diagnosis, affording them the opportunity to provide their respective NHS Trusts with informal feedback about the care and treatment they received as men with breast cancer. In some cases, their feedback resulted in changes being made to service provisions. Exercising the “duty of care” he described, Ewan, whose working role at the time involved developing print resources for NHS patients, was directly responsible for incorporating male imagery into future materials provided to those undergoing mastectomy surgery at that particular site:

“I was looking for images for me [of men] but I couldn’t find any so my pledge was right we’ll take some photographs we’ve got the clinic got the studio we’ll do it... so they use that actually to show men this is what you’re gonna look like in six months’ time an’ I think from a patient care point of view it’s a really good thing... I had nothing like this at all so it was a nice thing to do”

(Ewan, lines 273-275, 282-283)

Despite Ewan’s working role, only when he became a service user himself did he recognise the inadequacies of the materials being provided to men; hence his decision to be photographed across his illness trajectory, taking advantage of his unique position to personally facilitate change. Ewan clearly finds benefit in drawing on his own experiences to improve those of future persons affected by breast cancer, especially men, and in engendering
better awareness, avowing “I try and promote it as much as I sort of can” (line 1771). This is further evidenced in image 46, which Ewan captioned “Spreading the word”; a photograph of a newspaper article in which he featured, discussing his breast cancer experience:

![Image 46, Spreading the word, Ewan (lines 2173/2174)](image)

Several of the men interviewed chose to publicise their breast cancer stories, typically appearing in local press releases ranging from news articles – on- and offline – to radio broadcasts and featured items on TV programmes (see also Chapter 5 – 5.1.2.2.1). Many also engaged with breast cancer charities from local to regional and national organisations. This again was multi-beneficial; though the men (as many affected individuals do) predominantly viewed sharing their experiences and engaging with breast cancer charities as a means of ‘giving-back’ – consistent with men (stereotypically) positing themselves as providers rather
than dependants – most men admitted that they too gained from their various involvements with charitable agencies (see Chapter 7, 7.4). Ways in which these men benefitted included, re-developing a sense of purpose, and interacting with others (women and men) affected by breast cancer, aiding them in reconfiguring their masculinities and identities. Where some of the men described feeling obligated to become a breast cancer activist/advocate, others described it almost as if it were fated or a special calling (see also Ackroyd, 2016):

“I think I’ve been blessed because I can help t’ pass on the message to people and if I ‘adn’t got the cancer I wouldn’t a known about it and I couldn’t tell anybody about it an’ not as many people ’d know about it as they do now... the positive thing is the charity work I’ve raised money t’ help other people”

(Andy, lines 832-836, 933-935)

Andy viewing himself as “blessed” and positioning himself as a message-bearer is another example of how the men articulated finding benefit in the breast cancer experience. For Andy, engaging in knowledge-sharing and fundraising activities is a form of active coping; by focusing on the positive aspects to result from his diagnosis, his appraisal of the illness experience is seemingly more favourable, and improved coping ensues. Similarly, Neil also posited himself as a messenger of breast cancer awareness, conscious of the positive and far-reaching implications that publicising his breast cancer experience might have for other men:
“...it makes me feel good that in the future it’ll help men that get it... I am making more people aware that it exists all my male friends all my male work colleagues they all know now that men get it too and they’re all letting their families know so from me having breast cancer as one person ‘as made thousands aware that men get it and that can only be a good thing... the more people I can prevent going through the same ‘as gotta be a good thing”

(Neil, lines 96-97, 1309-1313, 1316-1317)

Given his struggles with getting diagnosed, Neil was especially keen for breast cancer in men to be more widely recognised and for greater breast cancer equality to be realised; clinically and socially. Happy to publicise his identity as a man with breast cancer, Neil and his immediate family all wear half-pink half-blue awareness wristbands (Image 47) in support of people affected by breast cancer; specifically intended to represent both sexes, in a bid to help reduce gender inequality in breast cancer promotion.

Image 47, Charity wristbands, Neil, line (1834/1835)

For Neil, the wristband serves as a conversation-starter, implicitly inviting enquiries about the cause he is visibly supporting:
“it’s on y’ arm and everyone can see it an’ if they wanna ask questions about the blue an’ the pink then that’s fine it just gives me a reason t’ talk… I think them being ‘alf an’ ‘alf gets the message across more”

(Neil, line 1870-1871, 1883)

Though Neil’s motivation for wearing the wristband is to publicise “the message” and better educate others about breast cancer, he too gains from this activism, since increased knowledge begets greater understanding (diSessa, 2008), and likely greater acceptance too (Fish, 2014).

The concept of giving and getting through engaging with breast cancer activism and advocacy is apparent across the men’s accounts, and is further exemplified by Michael; who, as described earlier, since being ‘in recovery’, now hosts an annual darts-themed fundraising event to raise breast cancer awareness and money for local oncology services in his community:
Michael explained how the event takes months of planning and organising, and importantly provided him with an opportunity for active mental engagement while recovering from breast cancer, particularly when he was unable to work. The event of mutual benefit to Michael and his local community, serves as a “coping mechanism” for him, providing focus, goals – i.e. setting fundraising targets, purpose and recognition; while the community benefits from the funds raised and subsequent improvements made to patient provisions at the local oncology unit, as well as the sense of togetherness the occasion engenders in the locality. This serving to revitalise his masculinity in terms of demonstrating his social worth and importance.

“I was treated so spectacularly well that I decided that I wanted to do something... because of what’s happened to me I am now raising money t’ help other people () that’s a big positive for me... I’ve turned prob’ly the lowest part of ma life into something really positive now and it’s something that I look forward to every year...it’s a coping mechanism I suppose for me”

(Michael, lines 747-748, 1515-1516, 1527-1529, 1678-1679)
8.5 New and improved relationships following the breast cancer episode:

“yes its changed relationships… some for the better” (Peter, line 735-737)

In this final subtheme, the concept of a reconsidered and reconfigured masculinity is discussed with regards to the men’s changed relationships post- breast cancer including; spousal relationships, relationships shared with family members, friends and colleagues, and also their self-relationships.

Many of the men recognised that their diagnosis had affected their existing relationships, generally in a positive way; their breast cancer seemingly bringing with it a greater sense of togetherness and unity, improved emotional connectedness, and a higher level of appreciation for the relationships they shared with significant others in their lives. Some also considered the bearing that the illness experience had in terms of them forming new relationships, articulating a newfound openness to engage with others; these changes collectively demonstrating a departure from traditional masculinity, allowing for less constrained self and social interactions post-diagnosis.

Experiencing breast cancer prompted many of the men to re-evaluate relationships in their lives, arguably thinking more critically about them than before their diagnosis; assessing their meaning, and the positive and negative effects of maintaining these relationships. In some cases, the men’s breast cancer diagnoses reinvigorated existing relationships, giving them greater strength and significance; while others which the men previously thought to be irreparable were restored. On the other hand, subsequent to reconsidering life post-diagnosis, some of the men called time on relationships in their lives which no longer fulfilled them. Though the latter maybe perceived as unfortunate, all of the men who recounted relationships ending – especially where they had ended the relationship – consequent to developing breast
cancer, articulated this as a positive outcome, contributing to them achieving greater life satisfaction post-illness.

As the majority of the men interviewed were either married or cohabiting with a partner at the time of their breast cancer diagnosis, many discussed their spousal/spousal-equivalent relationships; how the illness event affected such relationships, good and bad, physically and emotionally. Most men articulated their illness as being one of the biggest tests their marriage/partnership had ever faced, especially in terms of the sexual relationship they shared with their spouses/partners, as Jonathon noted:

“I mean there’s no sexual relationship between my wife and myself and that’s very painful for her but she’s understands... we have body contact er obviously and there are different ways of demonstrating love and affection rather than sex”

(Jonathon, lines 585-586, 631-632)

As earlier mentioned in Chapter 6 (6.4), although many of the men experienced strained sexual relationships post-diagnosis (either as a side-effect of treatment(s) and/or body image issues), like Jonathon, these men were keen to emphasise that their spousal/spousal-equivalent relationships were multidimensional, going far beyond sexual intimacy. Many discussed how turning their attentions to non-sexual aspects of their relationships engendered more intangible benefits, such as improved emotional closeness:

“it ruined the sex life completely but it’s brought... something else comes along then (. ) an overpowering sense o’ love an’ affection an’ appreciation (. )... I could get emotional about it I mean ‘ow I feel about it y’know it’s the kindnesses y’ do more kindnesses toward one another”

(Maurice, lines 1069, 1085-1086, 1091-1092)
Maurice valuing exchanging “kindnesses” over engaging in sexual activity further demonstrates a relaxing of hegemonic masculinity, which is represented (in part) by sexual potency (Connell, 1995). However, though he recognised these changes in his spousal relationship following his breast cancer diagnosis, Maurice was reluctant to fully attribute them solely to the illness event, suggesting that the improved closeness experienced may also be a product of his long-standing marriage, and possibly a consequence of aging. Nevertheless, several other men also noted similar changes between them and their spouse/partner following the breast cancer experience, indicating that there may be a direct effect, as Peter alluded to: “you draw closer it does that to you” (line 265).

Almost all of those who identified as married/cohabitants at the time of their breast cancer diagnosis highlighted the key role their wife/partner played across the course of their illness; many positioning them as their primary coping resource:
“it’s not until some’ in happens like my diagnosis and what happened afterwards that you realise how strong your relationship is (.) because it can go one o’ two ways... you can take your relationship for granted but it’s not until something like this happens you realise how you are there for each other and I wouldn’t a coped without K being there (.) at all”

(Michael, lines 1911-1913; 1918-1920)

Michael’s visual representation here is particularly illustrative of the unity between him and his wife; their hands almost intertwined, and wedding bands purposefully the stand-out feature, reflecting their unwavering commitment to one another. Though implicitly assumed, Michael’s accompanying comment explains how the strength of their relationship became more apparent in light of his breast cancer, as did the meaning of their marriage for him, and how greater awareness of this has further improved what was already a “really good relationship” (line 1938).

Similarly, Tom credits his wife for helping him to cope with the process of adjustment to illness, describing her as his “rock”, i.e. solid and strong, and her supportive nature as coming naturally in his time of need. Keen to acknowledge the centrality of his wife in his breast
cancer experience, whilst simultaneously wanting to protect her identity, Tom included a painted illustration to accompany his talk:

“oh she’s my rock (.) just so supportive... I went to the hospitals or whatever on me own but I always knew that when I come back S ’d be there to support me in so many ways...I really can’t stress enough how much she’s helped me out y’know I don’t really know how I mean I woulda coped cos you cope but she made life so much easier and never complained (.) and listened to me moanin’ hah”

(Tom, lines 1375-1379, 1402-1404)

As mentioned earlier (see 8.4, and Chapter 7 – 7.4), in adherence to hegemonic ideals, the men generally demonstrated a preference to depict themselves as providers of care and support rather than recipients. Yet, when discussions turned to spousal/partner support, almost all of the men recognised the benefits of a supportive spousal/partner relationship. Many men commended their spouses/partners on implicitly adjusting to the changes in their lives – both short- and long-term – brought about by the breast cancer diagnosis; the quality of the support they received possibly also why these men mostly opted against seeking professional support.
(see Chapter 7.5). Interestingly, a number of the men questioned whether they themselves would have shown such resilience and restraint had the roles been reversed: “I still would’ve done it but I’d probably done a bit a moaning with it” (Tom, lines 1400-1401); this further indicating the men’s approbation for their spouses/partners during their convalescence, and how the breast cancer episode gave their relationships new, and arguably greater, meaning.

Many men discussed how experiencing breast cancer sparked a newfound appreciation for important others who play a significant role in their lives, and vice-versa in some cases; the existential threat seemingly causing others to appreciate their existence at a more conscious level:

“…there’s this whole network of people and places and things make you pleased that you’re still around”

(Matthew, lines 956-958)

“I think people appreciate me more now having had the prospect of losing me...yes I mean you appreciate being alive and appreciate that other people are glad you are alive”

(Jim, lines 403, 706)

The men’s realisations of what their existence means to others, and the significant roles they play in other’s lives seemed to foster a sense of worth, belonging and importance, and in some cases, purpose too, where men felt their existence was critical to that of others. Paul, for
example, as the main caregiver for his ailing mother and several domestic animals expressed his concerns for the welfare of these dependents in considering his mortality: “if I’m not here what happens to them?” (line 2197). Identifying as a provider for these dependents, Paul is able to maintain a hegemonic male position; although adopting a caregiving role arguably reflects a relaxing of traditional masculinity, since this is more commonly associated with ‘being’ female. Nevertheless, feeling needed and valued fortifies his self-esteem, and recognising what he means to these dependents, in turn causes him to realise what they mean to him. In acknowledging the integral role of important others in their lives, and especially during the breast cancer episode, several of the men discussed feeling the need to demonstrate their indebtedness to these others and “payback” (Neil, line 718) those who supported them most. However, to owe somebody implies being in a subordinate position (Connell, 1995), again illustrating a relaxation of hegemonic masculinity as the men reconsider and reconfigure their lives post-illness.

Many of the men reported how family relationships improved subsequent to their breast cancer diagnosis. Several of the men’s accounts included visuals of family portraits, intended to represent the wide-reaching effects of their diagnosis, recognising the influences – negative and positive – on their families, and also the importance of family togetherness in times of adversity. Generally, most men articulated feeling a renewed sense of family closeness having experienced breast cancer: “it’s brought my family closer together as a unit I think we’re closer” (Neil, lines 710, 2357-2358).

Reasons given for why the men perceived their families to be closer following their diagnosis were varied, ranging from family members ending “petty trivial disputes” (Glenn, line 1696), placing greater value and importance on “family get-togethers” (Bill, lines 1673-1719), and realising the potential for loss and meaning-making associated with this. Some of the men
also recounted how their breast cancer diagnosis provided them with an opportunity to re-
build familial relationships which had prior become fractured or distant. For example, Ewan
discussed reconnecting with his estranged daughter post-diagnosis:

“I hadn’t had any dealings with my daughter for four years... I wen’ in for my op
came back she was there... weird as though nothing had happened... I’ve no idea why
she decided to come back into my life we’ve not talked about it since because she
won’t”

(Ewan, lines 1015-1019, 1125-1126)

Ewan articulated – verbally and facially – the strong emotions he experienced on coming to
from his surgery and seeing his daughter for the first time in years due to an unresolved feud
between them. Describing their reunion as “strange but comforting” (line 1129), Ewan fully
attributed their making-up to his diagnosis and evidently embraced the opportunity for
reconciliation. Somewhat paradoxically, though interested to know more about his daughter’s
decision to reunite with him, Ewan was seemingly contented should her reasons remain
unspoken; choosing to take their renewed relationship at face value, possibly cautioned by a
sense of self-preservation, but perhaps also his desire to maintain this repaired relationship. It
also demonstrates him relinquishing control, which again is typically ‘unmasculine’ (Matheny
& Cupp, 1983).

Several of the men admitted to taking others and their relationships somewhat for granted pre-
diagnosis and articulated this to no longer be the case following their breast cancer episode;
many viewing themselves as “lucky” (e.g. Ewan, line 2115) to be ‘in recovery’, and to be
able to reset and resume relationships. For some of the men, their breast cancer diagnosis
brought with it enlightenment and liberation, influencing various facets of their reconfigured
lives, including improved relationships:
“I wouldn’t say it was a relief because it wasn’t but we’d become a little dysfunctional and all of sudden we got together”

(Glenn, lines 530-531)

This concept of regaining perspective presented strongly across the men’s accounts, articulated with reference to multiple areas of the men’s lives, including dissolved as well as renewed relationships, as Robert and Peter’s comments reflect:

“when you have a problem like this in life you learn who your friends are...some have been absolutely wonderful some haven’t”

(Robert, Int.2, lines 436, 508-509)

“yes it’s changed relationships I had with friends... some for the better some not some drifted away because they found it difficult”

(Peter, line 735-737)

Though the majority of the men reported strengthened relationships, several also experienced relationship breakdowns subsequent to them developing breast cancer; typically, dissolved friendships, and often male friendships. Reasons the men gave as to why the dissolutions resulted ranged from the men themselves reportedly feeling emotionally and psychologically unequipped to sustain friendships during the illness episode; to so-called friends physically distancing themselves from the men, severing contact upon learning about their diagnosis. Interestingly, those who discussed relationship breakdowns tended to talk about the dissolutions positively; choosing to view the cessation of those relationships as advantageous for them, articulating this as beneficial for their post- breast cancer selves and lives longer-term, if not more immediately:
“It sorted the wheat from the chaff for me. I was not gonna put up with people that were not good for me... not gonna put up with shit anymore just gonna get on wi’ life. Surround me self with positive people and err that’s what I did.”

(Glenn, lines 614-620)

Glenn’s comments here also reflect a regaining of perspective; the breast cancer experience causing him to reappraise his existing relationships in terms of their meaning, his expectations and needs as he concentrates on his future self. Many men shared Glenn’s preference for associating with positive people post-diagnosis and distancing themselves from negativity wherever possible (see Chapter 7, 7.4); another common finding among people who experience chronic illnesses (e.g. Hyland, Sodergren & Lewith, 2006). This is possibly why most men elected to discuss strengthened repaired and new relationships over dissolutions, despite articulating these breakdowns to have a constructive effect.

Engaging with new people and embarking on new relationships post-diagnosis was a common theme across the men’s accounts, and a notable benefit of the breast cancer experience for many of the men interviewed. As previously mentioned in this chapter (8.2), experiencing breast cancer led to a variety of new social opportunities for the men, both on- and off-line, which in turn led to some men developing diverse relationships with people of diverse backgrounds; some forging unlikely friendships. For example, Graham explained how talking openly about his breast cancer at work caused him to engage with co-workers he previously only shared shallow relationships with:

“it got me closer to two or three or several colleagues... it probably helped me build a relationship with some people I might not have known so well”

(Graham, lines 753, 756-757)
Graham here refers to forming new relationships in a familiar context. However, when talking about the emergence of new relationships, generally this was party to the men engaging in new activities, with different communities, e.g. the breast cancer community. Many discussed how they had come to form friendships with breast cancer counterparts and the meanings attached to these relationships despite their infancy in comparison to other important relationships in the men’s lives. When speaking about breast cancer counterparts, the men typically used positive language and consistently expressed their awe for these individuals, describing them as “amazing” and “wonderful people” whom they were pleased to know, in spite of only coming together as a result of their ill-health.

8.6 Chapter summary

In contrast to Chapters 6 and 7, which together exemplify the primary challenges and difficulties the men faced in line with developing breast cancer, and the subsequent implications for their constructed masculinities; this chapter has focused on positive aspects associated with the illness event, and the men finding benefit in their breast cancer experiences, leading to them identifying with a reconsidered and reconfigured masculinity as they return to health or accept their mortality. The concept of a reconsidered and reconfigured masculinity is reflected in the ways the men articulated finding benefit(s) and personal growth post-breast cancer diagnosis; how it afforded them new and unexpected life opportunities, leading to a relaxing of strict masculine cognitions and behaviours; renewed their sense of self and others, and the meaning of pre, existing and future relationships; and served to influence the self-identities, masculinities and the lives the men constructed, or rather reconfigured, as they enter breast cancer recovery. As the idea of men relaxing their masculinities post-breast cancer has yet to receive much, if any, attention in the current literature base, discovering that (most) men establish a reconsidered-reconfigured masculinity during breast cancer recovery
presents as a novel finding; demonstrating further support for the originality of this research, and the application of the multi-method approach used to explore men’s breast cancer experiences.

As is illustrated by the schematic representation presented in Chapter 6 (p.137), though men adopting a reconsidered-reconfigured masculinity is indefinite, i.e. not finite, with them seemingly able to transition back and forth between the masculinities identified across the illness trajectory; based on the study findings it is argued that transitioning to this third masculinity is necessary for men for improved psychological adjustment to and beyond breast cancer. The collective findings are considered further in Chapter 9 as part of the general discussion; critically discussed in view of the research framework, questions and aims, previous and future research in the field.
Chapter 9 – General discussion

In this final chapter, a general discussion about the research programme as a whole is presented. The chapter begins by summarising the findings of the two-part inquiry (9.1), ahead of considering whether the research achieved what it intended (9.2); how men’s breast cancer experiences converge and diverge with those of women (9.3); and what the current research adds to the extant knowledge base (9.4). It also considers the limitations, challenges and strengths of the research (9.5), as well as implications and applications; with recommendations offered for clinical care and practice, breast cancer charities and policymakers (9.6). Ideas for future research are also discussed (9.7), followed by strategies for research dissemination (9.8). The researcher’s (and participants) reflections on the research process are then presented (9.9), before closing with some concluding remarks (9.10).

9.1 Summary of findings

Following on from the focused qualitative synthesis (study part one), which demonstrated how men with breast cancer navigate a series of biomedical, psychosocial and socio-political challenges across the illness trajectory, and presented a need for further research with men from diverse populations, using more nuanced and sophisticated methodologies (see Chapter 3.8-3.10 for a more detailed discussion of the synthesis findings); a new multi-method, critical qualitative inquiry exploring men’s breast cancer experiences was developed (study part two). Following an integrated IPA analysis of 31 British men’s verbal-visual breast cancer accounts, three interrelated superordinate masculinities were identified: ‘threatened and exposed’, ‘protected and asserted’ and ‘reconsidered and reconfigured’ masculinity, along with 14 supporting subthemes, and demonstrate how men encounter and perform masculinity across the breast cancer trajectory. A schematic representation was developed and presented
(see Chapter 6) to illustrate how these interconnected masculinities are exhibited by men from pre-diagnosis through their breast cancer journey as they manage, make sense of, and live through the illness experience. The findings show how breast cancer diagnosis initiates feelings of being threatened, particularly in terms of their masculinity, prompting them to protect and assert their male selves to uphold their hegemonic status. However, as they progress through the breast cancer episode and begin to reconstruct their lives post-illness, paradoxically, the men appear to relax their performance of masculinising practices, as they discover benefits associated with experiencing breast cancer; including opportunities for new life experiences and becoming a ‘better’ man. This concept of shifting masculinities among men diagnosed with breast cancer provides further support for Connell’s (1995) earlier proposal, conceptualising masculinity as plural rather than a single entity and as subject to change over time and place.

The first superordinate masculinity – threatened and exposed – exemplifies how the men discussed and illustrated the ways in which receiving a breast cancer diagnosis served to threaten their male identity. This is typically the first masculinity men encounter, exhibited in the early stages of illness when the men realise their vulnerability and the potential threats posed to their health and wellbeing, social roles and standings, and male embodiment. The men’s portrayal of threatened and exposed masculinity is reflected through their discussions and visual representations of felt and enacted marginalisation; perceived and actual clinical vulnerabilities; meaning-making of the physical, embodied breast cancer experience; and the perceived permanency of breast cancer in their lives following diagnosis. These together impinge on the men’s sense of self and masculinity, challenging long-established and previously taken-for-granted assumptions the men had formed about their constructed male selves over their lifespan, prior to breast cancer occurring. This finding is consistent with
earlier works which discuss how chronic illness can threaten masculine identities and potentially lead to identity dilemmas (Charmaz, 1995; Connell, 1995; Courtenay, 2000, Donovan & Flynn, 2007; Halls, 2013). It is also in accordance with Threatened Masculinity Theory (Mishkind et al., 1986) which posits that threats to masculinity result in body dissatisfaction and appearance-related anxieties, as previous studies of men and breast cancer have also shown (France et al., 2000; Pituskin et al., 2007).

The second superordinate masculinity – protected and asserted – demonstrated the men’s desire to maintain hegemonic or leading male roles and positions in their lives, and to preserve their social status and power despite their breast cancer diagnosis. This expression of masculinity typically comes after the men recognise their threatened and exposed positioning and sees them make various efforts to assert hegemonic masculinity and perform multiple protective behaviours, as they work to defend themselves against the relative masculinity threat. This included the men attempting to normalise breast cancer – especially in men; downplaying and downwardly comparing their diagnosis – particularly to breast cancer in women; contesting their need for support; causally attributing their breast cancer to male gendered practices; and searching for ways to prove their male credentials. This finding is in line with Courtenay’s (2000) supposition that health/illness behaviours provide men with an opportunity to exhibit ‘real’ masculinity to themselves and others, and to situate themselves in a masculine arena by ‘doing’ masculinity as it is socially prescribed. However, it is worth noting that this may be less applicable to men who start from a lower masculinity base, i.e. subordinated men, e.g. gay/disabled men (see Connell, 1995). It also relates to Cheryan et al.’s (2015) recent research which shows threatened men to deploy specific gendered strategies when their male identity is questioned, including disavowing female preferences, and claiming more stereotypical masculine attributes. Here, the men also illustrate this by
causally attributing their breast cancer to male practices. This links with Taylor’s (1983) writings about causal attributions and meaning-making in cancer patients; their search for causal meaning key to helping them understand the implications for their masculinity. Further, the findings associated with this superordinate masculinity corroborate the findings of earlier research on men and breast cancer (e.g. Naymark, 2006), and also Masculine Dysfunction Strain Theory (see Levant, 1996), which show how rigid conformity to traditional notions of masculinity can be problematic for men’s health, and specifically, hinder their adjustment to breast cancer.

The third and final superordinate masculinity – reconsidered and reconfigured – exemplifies the men’s changing perspectives on ‘being’ male, breast cancer, and life more generally following their breast cancer experiences. Reflecting on the illness episode and their changed selves accordingly, the men articulate positives in the illness event and finding benefit in their breast cancer experiences, leading them to identify with a reconsidered and reconfigured masculinity as they enter recovery and return to health, or accept their mortality. In contrast to the first two superordinate masculinities, this presents a paradox; the men unexpectedly transitioning from a resistive and protective masculinity, to a relaxed and seemingly diluted masculinity. This is reflected in the ways the men articulated benefit-finding and personal growth subsequent to their diagnosis; how it afforded them new and unexpected life opportunities; renewed their sense of self and other, and the meaning of pre, existing and future relationships; and served to influence the self-identities and masculinities they constructed, or reconstructed, post-diagnosis. Though the concept of traditional masculinity diluting as men reconsider and reconfigure their lives beyond the breast cancer episode is a novel finding, some of the findings associated with this superordinate masculinity lend support to earlier research. For example, Ackroyd’s (2016) writings about men with breast
cancer ‘finding value’ and experiencing ‘posttraumatic growth’, plus other studies which discuss benefit-finding in the context of breast cancer (e.g. Stanton et al., 2002) and other chronic illnesses, e.g. prostate cancer (Pascoe & Edvardsson, 2016; Thornton & Perez, 2006). Further, and in contrast to Halls (2013) findings, the men in this study exhibit evidence of successfully re-thinking their personal biographies (Bury, 1982) and male identities; managing the relative disruption, enabling them to regain continuity (Reeve, 2010), albeit modified.

9.2 Has the research achieved what it set out to?

Primarily, this programme of research endeavoured to answer the following research question: ‘How do men describe breast cancer and their experiences of the illness?’ Through adopting an innovative and synergistic approach to the study of men and breast cancer, using a combination of qualitative psychological research methods, the researcher argues the findings afford greater insight into, and a more comprehensive understanding of, men’s breast cancer experiences.

Integrating and triangulating the findings from the two study phases, the on-going marginalisation of men across the breast cancer trajectory, and how this impinges on men’s experiences of and adjustment to the illness are revealed. Findings from the qualitative synthesis suggest that current approaches to breast cancer care and advocacy serve to isolate men, potentially alienating and emasculating them; while patient management practices and informational resources intended for breast cancer patients unequivocally marginalise men. Outcomes from the new multi-method inquiry confirm these earlier findings, and further illuminate the difficulties encountered by men, and some of their coping strategies.

Overall, the experience of being diagnosed as a man with breast cancer presents as emotive and complex; as challenging and rewarding; and paradoxically, as marginalising yet also
The experience is emotive and complex in that men generally find the diagnosis, the constancy of breast cancer in their lives thereafter, and the embodied experience difficult to comprehend and accept. It is both challenging and rewarding, since men experience notable lows, especially during the diagnosis and treatment stages, but also extreme highs as they discover benefits associated with the breast cancer episode. Lastly, it is marginalising in that men with breast cancer are consistently under-acknowledged both clinically and socially yet liberating insofar as men feel able to relax their performance of restrictive stereotypical male practices post-illness.

In answer to the secondary questions posed (see Chapter 2 – 2.5), the study findings highlight the numerous and diverse challenges with which men diagnosed with breast cancer contend, and the frustrations that coincide with trying to manage these (see Chapters 6 & 7). The sample of men interviewed unequivocally viewed themselves as belonging to a marginalised minority community (see Chapter 6), and expressed a clear desire for greater equity, not only for men but for all affected by breast cancer, particularly in terms of care and support; many actively working to engender this as advocates/activists.

In addition to answering the research questions, the research also aimed to:

   i) gain an in-depth and holistic understanding of how men experience breast cancer

   ii) advance knowledge regarding men’s constructions and meaning-making of breast cancer and masculinities

   iii) ‘give voice’ to what is currently an under-researched minority group

   iv) offer recommendations for how to improve the treatment, care and support of future men who experience breast cancer
The researcher argues that the research programme has achieved these aims for the following reasons. First, implementing the photographic method alongside phenomenological interviews, and combining men’s verbal and visual accounts of the breast cancer experience has unequivocally added greater depth and understanding. Generating a visual account involved participants engaging with their thoughts, ideas and emotions over an extended time period, allowing for deeper contemplation leading to more insightful discussions and interpretation. The specific benefits of data amalgamation, including how and in what ways the researcher argues this improves understandings, is discussed further in sections 9.4 and 9.9.

Second, the research advances knowledge by newly identifying three specific interconnected masculinities that men with breast cancer identify with, perform, and move between, across the course of illness. The schematic representation used to illustrate this transitioning between masculinities also advances knowledge; demonstrating how men construct gender differently as they progress from pre-diagnosis through to initial treatment conclusion, while related interpretations consider why men do this and their associated meaning-making. To the researcher’s knowledge, this is the first study to reveal these shifting masculinities amongst men diagnosed with breast cancer, and to contemplate how the finding influences understandings about men and breast cancer.

Third, whilst acknowledging that the research did not really access poor, BAME, gay or disabled men, it has ‘given voice’ to people in a minority group that has been largely neglected in social science research. Uniquely, it has afforded men affected by breast cancer the opportunity to comprehensively express their ‘voice’ in two ways; verbally, through candid discussions, and visually, through self-authored images which for them best represent the breast cancer experience. Integrating the men’s verbal and visual accounts enriched their
‘voices’ and has expanded opportunities for these to be ‘heard’, as is discussed further in sections 9.4 and 9.7.

Lastly, in terms of making recommendations to improve future men’s breast cancer experiences, from analysing the men’s account-giving, a number of possible implications and applications are identified relevant to clinical care and practice, breast cancer charities, and policymakers. These are presented later in section 9.6. Some of the recommendations the researcher offers in relation to men and breast cancer share similarities with those proposed by Fish (2010) for improving lesbian and bisexual women’s experiences. As is discussed in section 9.3, men and women’s breast cancer experiences converge and diverge in various ways, and so do some of the experiences of men with other minority patient-survivor subgroups (Fish, 2010); thus, it is perhaps not surprising to see some overlap between the suggested changes for reducing inequities.

9.3 How do men and women’s experiences converge and diverge?

Though the intention of this research was to focus solely on men’s breast cancer experiences, it is important to acknowledge that several of the study’s findings are not exclusive to men, or indeed breast cancer. As noted already in the discussion that followed the qualitative synthesis (see Chapter 3 – 3.4, and Quincey et al., 2016, pg. 23), there are both similarities and qualitative differences in men and women’s breast cancer experiences. Several studies exist which compare breast cancer in men and women, though few of these are qualitative inquiries (e.g. Williams et al., 2003; Sime, 2012), and most have tended to focus on biomedical rather than psychosocial aspects (Anderson et al., 2010; Ly, Forman, Ferlay, Brinton & Cook, 2013; Vermeulen, Slaets, Cardoso, Giordano, Tryfonidis, van Diest et al., 2017). Further, there is little empirical research which systematically explores how men and women’s accounts converge and diverge; though it is possible to draw comparisons between previous syntheses.
focused exclusively on women (e.g. Howard et al., 2007; Jones et al., 2015) and men (Quincey et al., 2016), as the researcher does in Chapter 3 (3.4.3).

Some of the similarities and differences noted between the sexes in Chapter 3 were also identified in the visual voice study. For example, the findings from the latter provide further evidence of men, like women, engaging in strategic disclosure because it permitted normalcy and afforded them an initial maintenance of privacy whilst coming to terms with their diagnosis; this in contrast to women who have previously been shown to practice strategic disclosure to protect significant others from their illness, especially offspring (Hilton et al., 2009). Also, the use of battleground terminology was again common across the men’s accounts. Stemming initially from George Bush’s (2002) pledge to win the ‘war on cancer’, the use of combative language is common in postmillennial breast cancer research with men, and women (e.g. Garrison, 2007), and other chronic illnesses too; including dementia (Lane, McLachlan & Philip, 2013), and prostate cancer (Forbat, Hubbard, Place, Leung & Kelly, 2014). Though men and women with breast cancer use many of the same combative terms, e.g. “fight” “assault” “defeat”, they often differ in how they apply this language. As noted earlier (Chapter 3 – 3.4.3), in contrast to women who typically use it prospectively to motivate survival and overcoming the ‘war’ on their bodies (Garrison, 2007), as this research illustrates, men’s usage tends to be more retrospective; related to their altered masculine embodiment and reconsidered identities. For example, several men spoke of having “war wounds” or “battle scars”, articulating themselves as “winners”; both for “beating it”, and also winning in the sense that they had gained and grown personally from the illness experience.

Women finding benefit in the breast cancer experience is well documented (e.g. Tartaro, Roberts, Nosarti, Crayford, Luecken & David, 2005; Tomich & Helgeson, 2004; Sears et al.,
as is benefit-finding in other chronic illness contexts, e.g. Multiple Sclerosis (Pakenham, 2007) and HIV/AIDS (Kossakowska & Zielazny, 2013); though there has been little discussion of this previously regarding men and breast cancer (see Pituskin et al., 2007; Ackroyd, 2016). In this research, the concept of benefit-finding is newly discussed with respect to how this relates to men ‘doing’ gender; specifically, how they reconfigure masculinity through finding benefit in the breast cancer experience, demonstrating freedom from the constraints of performing hegemonic male practices. To the best of the researcher’s knowledge, research has yet to show that breast cancer has the same liberating effect for women in terms of how they perform femininity; if anything, it may have the opposite effect. As Kendrick (2007) argues, women’s recovery of femininity and feminine appearance is seen as central to them recovering health post breast cancer. However, in this study, relaxing masculine practices was central to men recovering health and improved psychological adjustment; thus, demonstrating divergence in how men and women perform gender when readjusting to health post breast cancer.

While men and women both experience role changes following a breast cancer diagnosis, particularly post-treatment, and often due to bodily restrictions, the researcher noted two reasons why role change is different for men and women. First, though there is evidence that both sexes can experience a reduction in the number and type of roles they are able to perform, research scarcely reports women performing typically male-gendered roles post-treatment; unlike men, who in leaving behind traditionally male roles, often take on new roles more commonly associated with women, e.g. providing social support to others. Second, socially constructed expectations about men’s ability to perform physically are different to those held about women (Coles, 2008), and arguably encourage greater role strain in men. For example, whether pre, during or post-breast cancer, and stereotypically speaking, women are
not expected to exhibit physical strength in the same way or to the same extent that men do (Sharma, 1994); therefore, losing such abilities are likely more meaningful for men, not least because they were lost as a result of developing a ‘female’ illness.

Men and women’s accounts of the embodied breast cancer experience also highlight similarities and differences. For instance, where some body image concerns are shared, e.g. a need for symmetry (see Henseler, Reinke, Vogt, Ray, 2015), others appear to be male-specific, e.g. not having the same freedom as other men to be shirtless and being unable to disguise mastectomy scarring in the same ways that women can, i.e. by wearing a brassiere. Breast prostheses do exist for men but are not readily offered to men as they are to women post-mastectomy; and, even if they were, men’s concerns about feeling exposed when shirtless would likely still persist, since this would only benefit men when worn under clothing. Interestingly, despite their body image concerns, none of the men interviewed had undergone breast reconstruction; reasons for this included concerns that it may look aesthetically worse, and also undergoing an additional and medically unnecessary surgery. There is evidence that some women who opt to ‘go flat’ share similar concerns to these (breastcancer.org, 2017). However, one difference the researcher noted was that men were most commonly averse to breast reconstruction because they erroneously classified it as cosmetic surgery, perceiving it as unmasculine, and thus undesirable.

Many of the men equated ‘being’ male to not being like a woman (Kimmel, 1994), and made various efforts to masculinise breast cancer by de-feminising it. One way they tried to achieve this was through causally attributing their breast cancer to male-gendered roles and behaviours. Though causal attributions are also common among women with breast cancer (see Peuker, Armiliato, de Souza & de Castro, 2016), ascribing the diagnosis specifically to gendered (male) practices is seemingly only something that men do. Some women do
however share the same desire that many men have to de-pinkify breast cancer and move away from the associated ‘pink ribbon culture’ (Sulik, 2011); which could also be regarded as a de-feminising practice.

Expressing a disinclination to engage with breast cancer support services is also not an exclusively male practice. That said, women appear to be less likely to contest their need for psychosocial support (Abrams, 2014). Though as discussed earlier (Chapter 3 – 3.4.3), this may be because, unlike men, women are socialised to seek support and be emotionally expressive (Moynihan, 2002). Reasons the men themselves gave for not wanting support tended to be gendered, such as perceiving support-seeking as a feminine practice and being stoic – a typically masculine trait (Green, 1998); thus, they diverge from women’s reasons.

Finally, the greatest divergence between men and women’s accounts relates to their experiences in clinical and professional settings. Whilst it is true that certain subgroups of women are overlooked/marginalised by clinical practices, e.g. lesbians, bisexual and younger women, there is greater evidence of this in the case of men with breast cancer. For instance, men reported being wrongly assumed and referred to as female and treated according to best practices for women. The gendered attitudes and behaviours that the men exhibited could then be a mirroring response, reflecting the gendered attitudes and practices they encountered in clinical/professional settings. For example, men not wanting to “encroach on spaces and services intended for women” may result from them being segregated from women in patient waiting areas.

9.4 What does the research add?

Though not the only criterion against which doctoral research is adjudicated (Clarke & Lunt, 2014), demonstrating originality, or providing evidence that the thesis contributes something new to knowledge, is a fundamental requirement; and that which the current research fulfils
for several reasons. First, with a sample that consists exclusively of 31 MEBs, the visual voice component of this research is the largest single qualitative inquiry to explore UK men’s experiences of being diagnosed with breast cancer. To date, only one other study has considered a larger number of experiential accounts provided solely by MEBs. Hunt et al.’s (2011) research project for healthtalk.org explored 33 men’s breast cancer experiences, amalgamating data collected specifically for that study with data already collected by Sime (2012) as part of her PhD research. Therefore, the visual-voice inquiry is the largest single qualitative data collection effort so far. As discussed earlier in Chapter 4, though larger samples are less common in IPA inquiries, as previously published studies have shown (e.g. Murray, 2004) they can be successful (Pietkiewicz & Smith, 2014), provided that full appreciation is given to each individual account, as the researcher has demonstrated here, by way of the individual theme tables developed for each man’s account. Working with a larger sample, whilst acknowledging that the research presents a particular perspective (Smith et al., 2009), is more representative of men’s breast cancer experiences than a single-case or smaller study (e.g. Ackroyd, 2016) would be. Further, qualitative PhD studies typically have an average sample of around 30 participants (Mason, 2010); further justifying the suitability of the 31-man sample employed here.

Second, this is the first inquiry around men’s experiences of breast cancer that is informed by critical health psychology (CHP), a perspective which considers health/illness behaviour within social, political and cultural contexts (Hepworth, 2006); thus, offering a new way of thinking about men’s experiences in comparison to existing psychosocial inquiries in the field which have consistently employed mainstream approaches. As Igarashi (2015, p.174) noted: “mainstream health psychology cannot achieve the goal of ‘health for all’”; something which CHP strives to engender by moving beyond individualism, positivism and ethnocentrism to
consider how lived experiences of health/illness are socio-culturally and politically situated, recognising the significance of inequality for health, and the need for critical reflective practice (Igarashi, 2015). Hence, in adopting a CHP framework, and also in drawing on PR, the research is additive in that it goes beyond recognising men’s marginal position (e.g. Halls, 2013) to explore and highlight the role that society, academia, health professionals, charities, policymakers and men themselves play in perpetuating this inequity; and, how change might be implemented – some recommendations for which are offered in section 9.6.1-9.6.3.

Third, as mentioned earlier in Chapter 3 (see also Quincey et al., 2016), the interpretive qualitative synthesis that was conducted on previous research exploring men’s breast cancer experiences, and which served to inform the subsequent visual-voice inquiry, is the first review of its kind to focus (and be published) on men and breast cancer. Through a collective evaluation of earlier research in the field, the researcher was able to expand current knowledge, generate further insight, and identify pathways previously either under- or unexplored. This ensuring that the photo-phenomenological study that followed had an additive consequence, rather than simply corroborating existing findings. For example, one recommendation coming from the synthesis was that future studies should use a more nuanced and sophisticated range of methodologies around men with breast cancer to better understand their male needs; hence the employment of the visual voice approach in the subsequent study.

Fourth, in addition to this research generating the first qualitative synthesis on men and breast cancer, it is also the first to explore men’s breast cancer experiences using a combination of photographic and interview data. This is an innovative approach to the study of men and breast cancer, and to the best of the researcher’s knowledge, is the first related qualitative inquiry to collect data by way of participant-authored photographs; the technique enabling
affected men to ‘give voice’ beyond verbal and textual practices, the importance of which earlier inquiries had largely overlooked, with the exception of Hunt et al. (2011) who video-recorded their participants interviews, to capture both verbal and nonverbal communications. Prior to this study, the choice method used to explore men’s breast cancer experiences was almost exclusively audio-recorded interviews, with only a few exceptions (e.g. Williams et al., 2003); thus, demonstrating how innovative the research is, adding to traditional qualitative methods and adopting a fresh approach in an effort to better understand men’s experiences, and advance knowledge regarding men’s meaning-making of breast cancer and masculinity. To quote Prosser and Loxley (2008, p.4) “visual methods can: provide an alternative to the hegemony of a word- and number-based academy; slow down observation and encourage deeper and more effective reflection on all things visual and visualisable; and with it enhance our understanding of sensory embodiment and communication, and hence reflect more fully the diversity of human experience”. Further, with regards to the combination of photographic and interview data, as Robinson (2011, p.116) commented: “the collection of participant imagery, especially when accompanied by participant’s own voice expressing personal thoughts and concerns, has a directness that both personalises issues and engages the viewer”. From the researcher’s perspective, the photographic method – as expected – provided this; adding another dimension to the men’s account-giving by enabling them to express their views as they ‘saw’ them, and the researcher in turn to ‘see’ from their standpoint. As demonstrated across the three analysis chapters (see 6, 7 & 8), there is a depth to the data – especially where the verbal and visual synergise – that serves to strengthen this research; setting it aside from previous work, even where findings overlap. Fifth, in terms of data analysis, it is also one of few studies to analyse men’s breast cancer accounts by way of IPA. At the time of formulating the research idea and deciding on the
methodological approach back in 2013, and when the qualitative synthesis was initially conducted (and went to press), there were no published IPA studies on men and breast cancer. Since then, two have emerged: Butterworth and Sparkes (2014) published an IPA case study of a middle-aged UK man in the early recovery phase of breast cancer; while Ackroyd (2016) employed IPA to explore the experiences of six US men, from a counselling psychology perspective. Still, to date, the current inquiry is the first IPA study situated within a CHP framework to explore a group of UK men’s experiences of breast cancer, and to use IPA to analyse men’s visual representations alongside their verbal account-giving; therefore, adding fresh material to the small body of related IPA research that now exists.

Sixth, few studies have focused as explicitly on men’s meaning-making of masculinity in the context of breast cancer, and how this changes over the course of illness. Specifically, this study is the first to concentrate on how men perform utilise and transition between masculinities – consciously or otherwise – in their adjustment to illness, and life beyond diagnosis and treatment. Further, the schematic representation (see Chapter 6) that is used to illustrate the shifting masculinities identified is also an innovative contribution. The research extends Halls (2013) work which focuses on men with breast cancer negotiating gender, and others (e.g. Sime, 2012; Ackroyd, 2016) which have given thought to how breast cancer in men affects male identity and masculinity. In particular, discovering that men (paradoxically) relax their performance of masculinising practices as they progress towards recovery and begin to reconstruct their lives post-illness, challenges previous suggestions that men strive to retain hegemonic masculinity.

Finally, the research also expands on previous (though limited) writings which refer to men finding benefit in the breast cancer experience; specifically, Ackroyd’s (2016) work which explicitly discusses ‘finding value in suffering’ and ‘posttraumatic growth’. While the
findings demonstrate some overlap with those presented here in relation to the reconsidered and reconfigured superordinate masculinity identified, this research has developed these themes further. For instance, the concept of men relaxing their masculinity as they discover benefits associated with the breast cancer episode is a new finding. Also, the photographs that the men employed to represent them finding benefit in the breast cancer experience offer greater depth and insight. Ackroyd’s (2016) use of the word ‘suffering’ also differentiates the two studies findings; her interpretations concentrate on men finding good in the bad, whereas here, the researcher also acknowledges the men realising what was already good about their lives, and how their experiences have underlined and enhanced this.

9.5 Limitations, challenges and strengths of the research

The researcher has identified a number of limitations salient to the second part of this research inquiry; some of which demonstrate overlap with those discussed earlier in Chapter 3 (see 3.9) relative to the qualitative synthesis (study part one), as the researcher reflects upon further in 9.9.

First, although participants were sampled from across clinical communities and online contexts, participants were disproportionately white and heterosexual. In spite of the overarching CHP framework and the researcher’s intention to recruit a more diverse sample of men than previous studies (see Chapter 3.9), the visual voice study included no BAME individuals, and few poor, young, disabled, gay or unmarried heterosexual men, despite the researcher’s efforts to reach out to wider communities. Further, the sample is also self-selected, meaning they may not be representative of the male breast cancer collective. Therefore, the researcher is cautious of claiming transferability to non-heteronormative populations. The pathway towards breast cancer recovery for men presented in the schematic representation (Chapter 6, p.137) may not fit men who were already in subordinated
masculinity positions (see Connell, 1995) as well as it does the current sample of mostly White, heterosexual, previously healthy and not-deprived men.

Second, the experience of being diagnosed with breast cancer for some men was close to 20 years ago which raises several concerns; including issues surrounding account-giving accuracy, the influence of time-lag on men’s response to the illness event, and changes made to policies, practices and the clinical management of men over this timeframe. However, information pertaining to men and breast cancer is still underreported, making it difficult to evaluate this. That said, the researcher noted more similarities than differences across the men’s accounts, irrespective of when they received their diagnosis. Further, the men’s accounts implied little had changed for men, clinically or socially, suggesting earlier experiences are equally as relevant as recent ones; though, traditionally, IPA tends to focus on current or recent experiences.

Third, despite the continued inclusion of a professional collaborator (i.e. a consultant breast surgeon) across the research, unfortunately, the collaborative endeavour to include a research partner never fully materialised. CHP and PR studies traditionally involve a co-researcher from the affected community at every stage of the research process, from identifying the research problem through to disseminating and actioning the outcomes, but this was not the case in the current inquiry; the research partner’s contributions, while valued and important, were minimal. Therefore, the research, although welcomed by MEBs, was largely professionally informed and researcher-led, rather than community- or co-driven, as was the intention. Thus, it does not fully achieve the collaborative goals of CHP (Lee, 2006) or PR (Cargo & Mercer, 2008).

Fourth, as the research focuses solely on men and breast cancer and does not explore men’s experiences with other reproductive cancers (e.g. penile, prostate and testicular) it is possible
that the masculinities identified and men’s performance of these masculinities may not be solely breast cancer specific. In order to establish which findings are exclusive to men’s experiences of breast cancer, further research with men and reproductive cancers is required.

Finally, the fact that not all participants engaged with the photo taking task can also be criticised. However, affording participants the choice as to which type of account they submitted is a more participatory approach, which is highly appropriate given the critical stance of this research; enabling those who took part to have their ‘voice heard’ irrespective of their participation choice.

Methodologically, and as the researcher and colleagues discuss in their recent paper (Papaloukas et al., 2017), integration of the verbal and visual data presented several challenges, including epistemological, practical and ethical issues; methodolatry concerns; participant engagement issues; and barriers to data analysis. First, the practical component of taking a photograph was a cause for concern for some participants and did in some cases deter men from participating in the visual aspect of the research. Physically engaging with photographic equipment to capture human experience should not be assumed straightforward in either the presence or absence of illness (Frith & Harcourt, 2007), though it is important to recognise the biophysical barriers that illness can potentially impose. In the case of men and breast cancer, reasons participants gave for declining to take part in the photographic component included physical restrictions brought about by their ill-health and/or elderly age; such as tiring easily due to the effects of anti-cancer treatments and having limited mobility post-mastectomy.

The unfamiliarity of the photo taking task highlighted a few points of concern, especially about the (deliberately) nondirective nature of the instructions. Some men struggled to comprehend the procedure, purpose and the practical steps needed to engage with the visual
task successfully and reported finding it difficult to visually depict intangible concepts (Burles & Thomas, 2014). In some instances, the undetailed nature of the instructions discouraged participants from contributing a visual account altogether: “I just didn’t get it like what you wanted me to do so thought best I leave that bit” (Darren). Participants frequently requested further guidance beyond that provided to them in the study information documents, especially with regards to what they should photograph. Some discussed having concerns about the relevance and/or artistry of their photographs and whether they were “good enough”: “Regarding the photographs, I am finding it difficult to think of something that is relevant” (Douglas), “I just pictured those that’d make a good photograph really” (Maurice). Some also gave thought to what other men might have photographed when generating their own account, demonstrating an element of competitiveness, but also their desire to impress and exceed the researcher’s expectations: “I tried to pick things that I thought perhaps no one else has done” (Ewan). Others were apprehensive about sharing intimate aspects of their lives photographically, cautious that visual materialisation of their realities through an enduring image might be too exposing and/or cause further strain. Several men queried whether it was compulsory to take photographs of themselves, more specifically, photographs of their altered bodies and mastectomy scars; for some, this was central to their decision-making about taking part: “I’ll do it so long as it doesn’t involve me taking my shirt off” (Michael).

Discrepancies between the participants and the researcher’s expectations also presented some challenges. It was not always possible to determine whether the participants were clear on what the task required of them, which sometimes led to the researcher having to clarify their expectations further, e.g. the minimum number of photographs participants were requested to take, and why it was necessary to give them little guidance. Some men struggled to understand that the visual component was about expressing breast cancer as they ‘see’ it, not
as the researcher envisages it. Participants also varied in their approach to the photo task, some rigidly adhered to the task as it was outlined, while others adapted it to suit their preferences; for example, using paintings rather than photographs, taking photographs of existing photographs/images, and creating a visual account using a combination of pre-existing and new photographs. The inclusion of pre-existing images raised a few questions ethically (see Chapter 5 – 5.4.4.3), causing the researcher to debate (together with the participant) the appropriateness of men using material which originally was never intended for use in research, as well as concerns about authorship and permissions to use existing photographs. Nevertheless, pre-existing images were included, largely for two reasons: first, many men were providing retrospective accounts about an experience that, for some, happened several years prior to them participating in the research, so the use of existing images served as a useful aide-memoire; and second, participants are entrusted to adhere to ethics, and provided that they do, affording them greater autonomy and control in generating their accounts is a critical aspect of CHP/PR/IPA research.

The vulnerability of the participant group highlighted the importance of adopting an empathic research stance (Larkin et al., 2006). As a socially marginalised group of people reflecting on experiencing a potentially life-threatening diagnosis, their accounts are pervaded by anxiety, existential angst and distressful feelings (Hunt, Nikopoulou-Smyrni & Reynolds, 2013; Quincey et al., 2016). Correspondingly, some men were understandably wary about exposing and sharing intimacies through visual representations which would then be scrutinised, concerned that this may potentially undermine what they considered to be adaptive coping strategies; affecting their engagement with the visual task. Issues and concerns about confidentiality in relation to the visual data were recognised from the outset and further defined throughout the research (Prosser & Loxley, 2007, see also Chapter 5). Further,
implications concerning authorisations to take photographs were also recognised. For example, men had to request permissions from appropriate personnel prior to taking photographs in clinical and/or professional settings.

Finally, the integration of the verbal and visual data posed a different challenge in relation to the analytical strategy employed; IPA. Given the infancy of using photographic data for an IPA methodological approach (Shinebourne & Smith, 2011), best practice for synergistically combining phenomenologically verbal and visual data is debatable. The paucity of guidelines caused the researcher to be additionally cautious when considering the analytical procedure. Photographs were carefully incorporated using general guidelines provided by IPA theorists (e.g. Smith et al., 2009) together with resources for guiding best practice with (solely) interview data to avoid misinterpretation of participant-generated meanings (Burles & Thomas, 2014).

Despite the challenges discussed, the research shows that methodological synergy is both possible and advantageous. Data amalgamation of this kind produces several methodological benefits, including rich and in-depth understandings of men’s breast cancer experiences within a CHP epistemological framework. First, the photo-authoring task affords participants both greater autonomy concerning the topics discussed, and also a more active role, enabling them to engage further with the research process. In addition, the time given to the participants has allowed for shifting the agenda in the subsequent interviews toward more participatory phenomenological research, and power dynamics toward a more egalitarian researcher-participant relationship (Balmer et al., 2015; Hurworth, 2003). All visual voice participants collected their photographs over a two-week period (sometimes longer if needed) prior to interviewing, affording them time to consider what was essential to them and their account-giving, and how they might articulate those tenets and ‘voice’ them – visually and
verbally – to the researcher (Burles & Thomas, 2014; Fritz & Lysack, 2014). This participatory approach of participants actively engaging in visual storytelling before arriving at the interview generating well-thought-out and detailed account-giving, while their continued involvement at different stages demonstrated consistency with PR and CHP traditions.

The inclusion of the photo task enabled those who generated a visual account to better articulate their lived breast cancer experiences, and associated thoughts and ideas with abundant meanings. The participant-authored photographs stimulated enhanced discussions and elaboration on aspects pertaining to the men’s everyday experiences, including struggles and successes; mitigating the barrier of expressing sensitive thoughts and experiences (Drew, Duncan & Sawyer, 2010; Switzer et al., 2015). Further, where men found it difficult to express themselves, photographs afforded them an alternative means for self-expression. For example, ‘Roy’ expressed the marginalisation of men with breast cancer by including a pink-hued image of a unicorn (Chapter 6, Image 1) together with the caption “mythical beasts, that’s what we [men with breast cancer] are” using this visual to articulate the feminisation of breast cancer, and his view that the illness in men is akin to make-believe social constructs: “We simply don’t exist.”

Synergy between the verbal and the visual has also assisted better comprehension of the participants lifeworlds, for which phenomenological research so vehemently argues. From a critical realist epistemology, it also argues that a participant’s lifeworld can only be partially unfolded and understood through a complex interpretative analytical approach (Larkin et al., 2006). Fusing the two qualitative methods together provided an opportunity for contextual, chronological, spatial and corporeal expansion in how men’s experiences with breast cancer are understood. The visual insights that some of the men provided as part of their in-depth
interviews serve to broaden understandings about their idiographic life experiences. For example, participants shared visuals closely connected with their embodied identity, including images of their pre- and post-mastectomy bodies, specifically photographs of mastectomy scarring and hair loss.

The researcher also considers that integrating the two data formats has profoundly benefitted data interpretation. Not only did it reduce the potential for misinterpreting participants meaning-making, embedding visual account-giving within the context of phenomenological interviews also enabled photographs to be understood in greater depth, and in the context of the individual; strengthening comprehension of the existential breast cancer experience. The men’s interactions with their photographs provided additional opportunities for the researcher to enhance both their empathic and interrogative interpretations (Flick, 2013). Moreover, the use of photographs amplified the men’s phenomenological accounts by enhancing their contextualisation, affording an epistemological openness (Larkin et al., 2006, p.114) which enabled superior illustration of their essential meaning-making (Reid et al., 2005; Smith, 1996).

Lastly, and importantly for the participatory element of the theoretical framework, data synthesis has expanded opportunities for research dissemination and practical applications reaching multiple audiences, including academics (within and beyond the field), the public, health professionals, cancer charities and policymakers (Catalani & Minkler, 2010; Plunkett et al, 2013); affording members of this marginalised group opportunities to have their ‘voices heard’, and a platform from which to become active communicators of the issues salient to men with breast cancer. The particulars of planned dissemination opportunities to date are discussed further in 9.7.
9.6 Implications and applications

In exploring and interpreting the findings from this two-part inquiry, the researcher has identified a number of implications and applications salient to clinical care and practice, (breast) cancer charities, and relevant policymakers. The researcher therefore makes the following recommendations specifically for improving men’s breast cancer experiences; these are thought to be especially relevant for the local hospital and consultants with whom the researcher collaborated with, though some suggestions may be applicable to the wider breast cancer community too.

9.6.1 Recommendations for clinical care and practice

- Though the men interviewed were not averse to the pink breast cancer culture, redressing clinical settings to appear more gender and culturally neutral may help to foster inclusivity, not only for men but all patients.

- It is imperative that all patients feel safe, secure and welcome in the clinical environment. Increasing the visibility of men in breast cancer resources and displays in clinical waiting areas would help to improve men’s sense of identity and belongingness.

- Making men, their needs and experiences more visible in staff training materials will improve staffs’ knowledge and understanding of breast cancer in men.

- It is recommended that healthcare professionals use neutral language when communicating with patients, and that patients are addressed by their name rather than title (e.g. Mr). Professionals are also encouraged to avoid making assumptions about men’s sexuality, and to have an awareness of support options available for men who identify as non-heterosexual.
• Shared patient resources with sections detailing male-specific needs and concerns are preferred to separate literatures which could unintentionally imply more differences than similarities between the sexes.

• Irrespective of whether men utilise support and aftercare services, making such services available and accessible to men may foster men’s sense of belonging, while affording them greater choice over clinical care options would likely empower them. Clinicians are advised not to make assumptions about men’s attitudes towards certain treatment and aftercare options, e.g. breast reconstruction.

• Providing additional opportunities for men to engage in clinical studies is vital for improving men’s experiences. Clinicians are therefore advised to encourage men to participate in breast cancer research, to make men aware of research participation opportunities, and to advise policymakers of the importance of this for improving men’s experiences.

• Health professionals should also actively encourage men to give feedback on their experiences of clinical care, practices and services, and use this feedback to improve future men’s experiences.

9.6.2 Recommendations for (breast) cancer charities

• When developing resources, ensure that imagery (photographs and diagrams) of both men and women, of different ages ethnicities and sexualities are included, to illustrate the diverseness of the breast cancer community. De-pinkifying/un-gendering breast cancer is desirable, though this does require careful consideration to protect those who engage with pink culture and associated funding for breast cancer research and support.
• Information that is intended for men, be that printed resources or online, needs to be clearly signposted and made easily accessible from the opening page/homepage. Some useful resources already exist for men, particularly online, but are often obscured by female-focused material.

• Ensure that services and promotional events, wherever possible, are equally welcoming and relevant to men as they are to women.

• Encourage inclusivity in online forums by explicitly informing users that discussions are open to all, but also offer specific spaces where subgroups can interact separately if preferred. For example, spaces for men-only, Gay/Bisexual/Trans/Queer men with breast cancer, etc.

• Ensure that men have a ‘voice’ and are made visible within the breast cancer community. Encouraging men to engage more with breast cancer events and activities, especially during breast cancer awareness month might improve this.

• Embedding information for men and women within the same documents/displays/advertisements/websites is preferred rather than separate gender-specific materials.

• Men demonstrate a need for data, statistics and other factual information that are relevant specifically to breast cancer in men. Charities could be encouraged to commission research or lobby research bodies to collect data on men as well as women, and work with participants to disseminate findings.

• Monitor men’s engagement with services, both on- and off-line, and encourage men to provide feedback as service users to ensure that their needs are being recognised and managed appropriately.
• Develop resources and provide useful links for significant others supporting men with breast cancer to ensure that these individuals are well-informed and feel recognised.

9.6.3 Recommendations for policymakers

• Current guidelines for the diagnosis and treatment of breast cancer provided by The National Institute for Health and Care Excellence (NICE) include very little information about breast cancer in men, despite offering recommendations for other patient subgroups, e.g. pre- and post-menopausal women. It is recommended that future releases and updates include more information and guidance about men.

• The National Cancer Intelligence Network (NCIN) and The National Cancer Equality Initiative (NCEI) have produced a number of publications which focus on breast cancer, including specific documents for breast cancer and deprivation, ethnicity and age. Detailed breakdown information for breast cancer in men though is lacking, therefore it is advised that NCIN and NCEI make it clear what available information is relevant to men and encourage health professionals and researchers to gather data on men.

• Information displayed on the World Health Organisation’s (WHO) website pertaining to early detection and screening for breast cancer exclusively refers to women. It is recommended that this site is updated to, at the very least, make site users aware that men also develop the illness.

• Encourage the Health Research Authority (HRA) to be more cognisant of men’s interests in breast cancer research, and potentially provide men with more opportunities to participate in research, ensuring that they feel safe and supported when they do.
- Policymakers should consult with men to determine preferred terminologies to use when referring to breast cancer in men in policy documents, since not all men identify with established gender labels, e.g. he/male/Mr.

- Consider funding research projects dedicated to studying men as well as women with breast cancer, especially clinical trials.

9.7 Ideas for future research

In terms of future inquiries, there are several ways to progress the research beyond the current research programme. Preferably, ideas for future research in a CHP context should be community-led or at least co-identified, though admittedly, some of the ideas presented below are more researcher-driven; guided by the outcomes and shortcomings of the current two-part inquiry. Therefore, the following suggestions can be thought of as ‘acorn ideas’, requiring further development and refinement through genuine collaborations with the community members, their relatives, and various stakeholders, if they are to evolve into true CHP inquiries.

One possibility is to explore the data from this study further by applying discourse analysis to the men’s breast cancer accounts; focusing on the role that language plays in men constructing an understanding and depiction of their breast cancer experiences, and masculinities accordingly. Though the decision to initially analyse the data by way of IPA is fully justified, given the epistemological stance and key research question and aims, to follow this up with a discourse analysis may further improve how the experience of breast cancer in men is understood, insofar as how it is linguistically expressed by those affected. Smith and colleagues (2009) previously discussed how some discursive approaches share some of the same concerns and interests as IPA, particularly Foucauldian discourse analysis (FDA), which they suggest has the “potential for fertile links” with IPA, given its “shared concerns with
how context is implicated in the experiences of the individual” (p.195). While IPA studies – as this research does – focus on people’s involvement in context and meaning-making (Smith et al., 1999), FDA examines the structure of the context and the resources available to the individual in making sense of their experience, such as ‘discourse’; viewing this as a “body of knowledge” or way of understanding their sense-making (Smith et al. 2009, p.195). Further, FDA is especially interested in linguistic expressions of power relationships in society; thus, is well-suited to critical psychological inquiries, including explorations of masculinity and breast cancer.

As Seymour-Smith (2015, p.2) noted, “language is central to most research practices in health psychology” and is treated as action in discursive approaches that primarily consider “how health and illness are constructed, oriented to, and displayed in social interactions”. Using discourse analysis to further explore the data might then reveal additional themes to those identified using IPA, as well as the language that men use in constructing the representations of masculinity identified here; allowing the researcher to identify commonalities (and differences) in men’s use of language when describing the male breast cancer experience. To date, very few studies have used discursive approaches to analyse the men’s breast cancer experiences (e.g. Halls, 2013). Therefore, further discursive inquiry would add to this currently limited body of research and enable a fuller understanding of existing findings.

One of the criticisms of earlier research exploring men and breast cancer noted in the qualitative synthesis (see Chapter 3, and Quincey et al., 2016) was that participants in previous studies were disproportionately White. As mentioned above (9.5), this was also the case in the visual voice study, despite the concerted efforts of the researcher in trying to recruit men from BAME populations via charities and equality organisations. Therefore, to date, the views and experiences of non-White men diagnosed with breast cancer and/or
racial/ethnic variations in men’s experiences with the illness remain very much underexplored and underrepresented. Future research on men and breast cancer should then look to rectify this imbalance, by actively seeking to include men from different ethnic and cultural backgrounds; not least because research indicates that Black men have a higher incidence of breast cancer, are more likely to be diagnosed at a younger age and have higher mortality than White male counterparts (Sineshaw, Freedman, Ward, Flanders & Jemal, 2015). However, these findings are based on US data, where breast cancer incidence rates for men are typically higher than in other geographical areas, e.g. Europe and Asia (Contractor, Kaur, Rodrigues, Kulkarni & Singhal, 2008). Nevertheless, literature on American men and breast cancer, especially experiential research, is equally as scarce as studies exploring the breast cancer experiences of men from BAME populations. Thus, the current dearth of US data presents another opportunity for future research when studying men and breast cancer; something that the researcher has already begun to explore, after interest from several US men in the current study, following the recruitment drive for UK men via social media. Visual voice interviews have already been conducted with three US men, and the researcher intends to expand on this, following completion of the current research programme. The initial aim is to produce a photo-phenomenological paper that focuses exclusively on US men and breast cancer, and possibly a follow-up article, comparing the experiences of US and UK men; making further use of the current study data which, as it stands, would offer another novel contribution to the field, insofar as advancing cross-cultural understandings about men and breast cancer.

As well as prioritising the recruitment of men from BAME populations and examining breast cancer in men across cultures, future inquiries should actively seek to explore the breast cancer experiences of men who identify as non-heterosexual. Previous research into men (and women) and breast cancer demonstrates as being heterocentric and heterosexist, and to date,
has largely overlooked the breast cancer experiences of non-heterosexuals; though a small body of literature does exist exploring lesbian and bisexual women’s accounts (e.g. Fish, 2010), and how their experiences fare in comparison to heterosexual female counterparts (Fobair, O’Hanlan, Koopman, Classen, Dimiceli, Drooker et al., 2001). As Quinn and colleagues (2015) noted, currently, there are no published studies on incidence and mortality rates for breast cancer among non-heterosexual men, while peer-reviewed qualitative research is also lacking; thus, presenting as an area in need of research attention.

Only one gay man contributed data for the current study. However, the findings of which, on initial consideration, suggest that there may be differences in the way non-heterosexual men experience breast cancer compared to men who identify as heterosexual; given that the male breast may typically play a different role in gay male identity and sexuality. This, coupled with some of the findings with non-heterosexual women, e.g. experiencing difficulties coming out to healthcare professionals, and hospital staff undervaluing their same-sex relationships (see Fish, 2010), invites further inquiry. Hence, following receipt of a small grant from the university, the researcher has recently started to recruit MEBs who self-identify as gay or bisexual for a small-scale international study, using the same visual-voice approach as the current study, so that data can be pooled with those already collected from two other studies. Furthermore, the researcher has also liaised with a founder-member of the ‘Male Breast Cancer Coalition’ (malebreastcancercoalition.org) about the possibility of collaborating to develop resources to support transgender persons diagnosed with breast cancer; another minority patient subgroup that is currently overlooked both clinically and within academia, and thus invites exploration.

In addition to studying the experiences of men themselves, future research should also consider exploring the experiences of men’s significant others; specifically, men’s
spousal/spousal-equivalent partners. In accordance with earlier research (e.g. Hunt et al., 2011; Sime, 2012), the current study again highlighted the central role that significant others play in men’s experiences with breast cancer. Spouses often served as the men’s sole or preferred source of support, shouldering household and, in some cases, financial responsibilities too during the breast cancer episode. These pressures, coupled with the unusuality of the diagnosis in men, causing additional stress to that of the threat of potentially losing their partner; which alone has the propensity to cause psychological distress. While there is a growing body of psychosocial research exploring the experiences of male spouses of wives with breast cancer (e.g. Zahlis & Lewis, 2010; Neris & Anjos, 2014), to date, the experiences of spouses whose male partner develops breast cancer are comparatively under-researched and largely unknown. Further, there is currently a paucity of informational resources and/or support services available for people supporting men with breast cancer; something which needs to be addressed, not least because, as the findings suggest, men tend to favour spousal/familial support over formal options. Thus, it is critical that researchers include men’s significant others in future inquiries to understand the needs of those providing this informal support, so as to prevent additional – and potentially avoidable – strain on men and their closest support providers. Furthermore, direct feedback received from the small number (five) of spouses/partners who sat in on some of the interviews for the current study suggests that significant others would welcome the opportunity to give and have their ‘voices’ heard. Formalised patient and public involvement (PPI) going forward could then be beneficial for affected men and their significant others; one possibility would be to carry out a focus group with various stakeholders (affected men, relatives, health professionals, charity personnel, sponsors etc.) to learn what their individual views and priorities are, and how they might be integrated to improve the experiences of all concerned.
In the same way that the experiences of men’s spousal/spousal-equivalent partners have been overlooked, so to have the experiences of single men diagnosed with breast cancer. Despite research consistently highlighting the important role that spouses/partners play in patients adjusting to a cancer diagnosis and increasing interest in how couples cope with cancer (e.g. Baik & Adams, 2011); surprisingly, facing cancer as a single person has to date received little research attention. Exploring the experiences of single men diagnosed with breast cancer may be particularly important, given that breast cancer incidence is typically higher in older men, who – statistically speaking – are more likely to be divorced, or widowed (Office for National Statistics, 2015). Research shows that older single men have the smallest social networks, are less likely to receive support from adult children (Novak, 2015) and are more likely to postpone or forego healthcare altogether (Keith, 1987); thus, presenting as potentially more vulnerable to poorer physical and psychological health outcomes, and death, when compared to married counterparts (Gomez, Hurley, Canchola, Keegan, Cheng, Murphy et al., 2016).

Exploring the experiences of single men with breast cancer may be especially useful for healthcare providers, as those who access healthcare may be more likely than married/partnered men to depend on the healthcare system/services for support, since many spouses/partners also serve to be informal care/support givers for cancer patients (Romito, Goldzweig, Cormio, Hagedoorn & Andersen, 2013). The current dearth of literature on single men and breast cancer presents as another opportunity to make a novel research contribution to the field, which potentially could have important applications for the breast cancer community, clinical care and practice, and academia. That said, despite recognising the need to study such groups, the researcher is mindful of the potential challenges in recruiting these men.
The final suggestion for future research is to further explore the experiences of breast cancer professionals who treat and care for men diagnosed with breast cancer. Recent research by Speirs (2015) stated that communicating with and caring for men diagnosed with breast cancer is often challenging for practitioners; calling for improved awareness among healthcare professionals about the condition and how to manage men’s needs. A small number of studies (Williams et al., 2003; Naymark, 2006; Halls, 2013) have previously conducted interviews/focus groups with either breast cancer practitioners or charity personnel; though not exclusively, and not previously using visual methods or IPA to analyse the data. Therefore, applying the visual voice approach used in this study to a sample of breast cancer specialists would potentially offer new insight and further understandings about their experiences of diagnosing, treating, caring for and supporting men. Exploring the experiences of breast care nurses may be particularly insightful, since surveys have previously shown that male breast cancer patients report breast care nurses as being the most helpful and supportive of all healthcare professionals (Speirs, 2015). Therefore, it would be valuable to examine their perspective on supporting men, and how similar/different they consider men’s needs are to women diagnosed with breast cancer. Further, it may also be interesting to explore commonalities/differences between clinical and support services, and how these converge and diverge in managing men with breast cancer; the outcomes of which could potentially inform and improve future breast cancer care and practices.

9.8 Strategies for research dissemination

In terms of research dissemination, outputs have been consistently disseminated throughout the research process, communicated mainly to academic and professional audiences, but also to the research population; maintaining a dialogic relationship between the researcher and the researched (Simon, 2013) which is key in CHP and PR inquiries, and importantly
acknowledging the men’s ‘voice’ at regular intervals, satisfying the community-engaged
element of this research. In accordance with good quality critical qualitative research (Elliott
et al., 1999; Fontana, 2002) and good practice for IPA inquiries (Smith et al., 2009),
progressive dissemination enabled continual reflections on the research as it happened, in
addition to the retrospective reflexivity that IPA researchers typically engage in to improve
research skills and enhance future inquiries (see 9.9). By disseminating outputs periodically at
different stages of the research, and reflecting on feedback received in real-time, this afforded
the researcher the opportunity, where appropriate, to incorporate advice and recommendations
offered as the research progressed, benefitting both the practice and writing up of the
research.

To date, two academic papers based on this inquiry into men and breast cancer have been
published in peer-reviewed journals: the first, a review article which presents the qualitative
synthesis outlined and discussed in Chapter 3 (Quincey et al., 2016); and the second article
(Papaloukas et al., 2017), presents a reflection on the process of combining photographs and
interviews in phenomenological inquiries exploring marginalisation and chronic illness
(discussed in part in 9.4). Additionally, a host of presentations (eight, so far) focusing on
methodological aspects of the research, key study findings and recommendations for future
breast cancer practice have also been delivered at a number of national and international
conferences, attended by experts in qualitative methods, men’s health and breast cancer, e.g.
the Association of Breast Surgery Conference 2016 (see Quincey, Shokuhi, Williamson,
Wildbur & Appleton, 2016). Further, and in keeping with the central premises of both CHP
and PR, i.e. to involve and predominantly benefit the research population (Murray, 2015;
Cargo & Mercer, 2008), communications were sent periodically to the study participants via
social media and/or email informing them about dissemination events and publications in
press/print. It is also the researcher’s intention to provide all study participants with a lay summary on completion of the research programme which will outline the key research findings and how this information might be implemented, both in theory and practice, to improve men’s breast cancer experiences. As Fernandez, Kodish and Weijer (2003, p.18) discussed, informing study participants of research outcomes is an “ethical imperative”, particularly in CHP research which seeks to uphold the highest ethical standards (Hepworth, 2006); “investigators owe a debt to the many participants who place their trust in science, without whose collaboration the search for new knowledge would be severely impeded” (Fernandez et al., 2003, p.18). This thinking seems especially applicable in the context of men and breast cancer, as recruiting from such minority populations is arguably more challenging, yet vital if we are to advance understandings about this relatively rare condition.

In keeping with the premises of CHP and PR, future plans for further dissemination are also aimed at both informing and involving the men who participated in the research. Specifically, the researcher – with input from the study participants – intends to develop a photographic exhibition showcasing a selection of the poignant and powerful imagery included by the men who submitted visual accounts of their breast cancer experiences. Academic contemporaries, clinicians, personnel from breast cancer charities, patient-survivors and other interested persons will all be invited to attend this public event to explore the experiences of the men who took part in the research, through photographs and other exhibits suggested by and co-created with the study participants. To ensure quality, the researcher plans to apply for funding, initially through ‘DMUengage’ (a local initiative open to De Montfort University students and staff, focused on funding research engagement activities) before inviting breast cancer charities to co-fund and collaborate on this event. From an originality perspective and thinking again about what this research can add to the field and relevant communities, to the
best of the researcher’s knowledge, the event would be the first of its kind relating specifically to men and breast cancer; though similar Photovoice-inspired exhibits have recently been used to successfully disseminate research looking at other chronic illnesses and minority populations (Papaloukas, 2017).

As noted in earlier chapters (4 & 5), this research does not strictly adhere to traditional Photovoice methodology as it is prescribed by Wang and Burris (1997), rather it is an adaptation of the method. Nevertheless, photographic exhibitions are typically the culminating event of a Photovoice project and are essentially what distinguishes it from other similar methodologies, as it endeavours to empower the study population and reach out to policymakers and leading representatives (Latz, 2017). As Latz (2017, p. 142) explains: “through Photovoice exhibitions, participants are afforded the opportunity to showcase their images and narrations of those images in profoundly meaningful ways”, while the dissemination of these findings “can foster empathic understandings about human life”; therefore, fulfilling two of the key research aims, i.e. to ‘give voice’ to men affected by breast cancer, and to improve understandings about the illness, hence the suitability of this dissemination tool to the current inquiry.

Beyond the exhibition event, the researcher also plans to produce another summary document about the research that will be communicated to relevant charities, including Breast Cancer Care who helped to facilitate the recruitment of study participants, and the ‘Male Breast Cancer Coalition’, a non-profit patient advocacy organisation; some members of which also participated in the research. In addition, a report will also be generated with the purpose of informing clinicians. Initially, this will be distributed to the NHS consultant breast surgeons with whom the researcher liaised with across the research, with the aim being to collaborate further with these clinical leads to produce an informational resource for the NHS. This
collaborative partnership has already produced an output offering recommendations for advocacy and intervention for improved future care and breast cancer practices which was presented at the Association of Breast Surgery’s annual conference 2016, with the corresponding abstract later published in the European Journal of Surgical Oncology (see Quincey et al., 2016).

As well as the two journal articles already in print, the researcher expects to produce two further academic papers based on some of the research findings. The first of these will concentrate specifically on the identification of shifting masculinities amongst men diagnosed with breast cancer; findings which currently stand to make a novel contribution to the field and academia. The second paper will focus on men finding benefit in the breast cancer experience, since this to date has received little research attention; demonstrating as an opportunity to expand knowledge in this area. However, to quote Anton Chekhov “knowledge is of no value unless you put it into practice”, and/or from a CHP perspective, unless it reaches the intended audiences and beneficiaries. Therefore, it is imperative that the current research findings and plans for dissemination are discussed further with the affected community before being actioned, since their input could be critical in terms of maximising research impact.

9.9 Reflexivity

The last section of this chapter concentrates on reflexivity; a central component of good quality experiential qualitative research (Shaw, 2010; Langdridge 2007; Finlay 2002), and is essential to an inquiry that is informed by CHP and PR and which employs IPA, all of which argue the importance of reflective practice for researchers and participants (see Chapter 4). Hence, an amalgamation of the researcher and study participants’ reflections are presented, demonstrating how reflexivity is embedded within the research process.
9.9.1 Personal reflections

As a woman, who has never experienced breast cancer or indeed, thankfully, any other chronic illness first-hand, and as a researcher who is considerably younger than the study’s participants, I see myself very much as an ‘outsider’ in this research endeavour. Not being a member of the breast cancer and/or male communities, some men were intrigued as to why breast cancer in men, and men’s health, would be of interest to me. Despite their curiosities, they did not seem to perceive the space between my ‘outsider’ position and them as problematic, or as an impediment to the research process; rather, quite the opposite. Some found my distance from their situation to be particularly beneficial, offering them an outlet for their emotions: “I couldn’t speak like this about it with my wife it would just be too upsetting for her” (Bill). Several of the men (unprompted) remarked that they were glad I was female, disclosing that they would have found it difficult to talk as candidly with a male researcher, concerned that he may have judged them and/or showed less compassion. One of my concerns prior to conducting the interviews was that the men would think/feel the opposite to this, and that my female gender might discourage them from disclosing certain information; but many said it made it easier to talk: “women are more forthcoming than men” (Maurice).

Some though did admit that the dynamic of the female/male researcher-participant relationship did affect their interactions with me. For instance, how they expressed themselves; refraining from using profane language or apologising on occasions where they did, because I was female: “I’m aware of some of the sensitivities because there’s a male/female divide” (Jonathon). On the few occasions that men explicitly referred to their use of language, I did explain that the rawer and more uncensored their account-giving was, the better; the very point being to ‘give voice’ in their own words, however they should choose to
express the breast cancer experience. I felt it was important to remind these men of this, and in some cases, it did lead to men relaxing their linguistic choices and improve rapport.

By and large, the overwhelming response from the men was one of gratitude; grateful that I had shown an interest in breast cancer in men and listened to their personal stories. I think I had underestimated the importance of this for these men, and also how keen they would be to engage in the research, since men – particularly older men – can be difficult to recruit; especially for studies that involve them talking about their health (Anderson, Seff, Batra, Bhatt & Palmer, 2016). Being a minority population, I expected the recruitment process to perhaps be more challenging than it was. Contact did ‘go cold’ with a few men who initially expressed their interest in the research which was disappointing, and two men regretfully had to withdraw due to their deteriorating health; this reminding me about the realness attached to human research, and that for those affected, it is not just a research project, but real life.

Whilst I fully acknowledge my ‘outsider’ position, I consider that a number of the experiences I encountered across the research process drew me closer to the study population and motivated me to pursue the research when at times, overwhelmed by the PhD process, I considered giving up. While I recognise that knowledge about breast cancer in men remains relatively low, people’s (lay/academic/professional) ignorance surprised me. It was not uncommon when speaking about the research for people to respond with laughter; either because the concept of men having breasts amused them, and/or out of disbelief that men could develop the illness. I remember, as part of a doctoral study training course, being asked to present a micro-teaching session to fellow PhD peers on the topic of my research. At the end of the micro-session, one man asked if I was joking or whether it was a genuine condition. He had no idea that breast cancer could be a reality for men. This exemplifying, for me, why it presents as a critical public health issue in urgent need of research attention.
In the early stages of the research I liaised with a variety of breast cancer professionals to improve my knowledge about diagnostic procedures, treatments and aftercare for men. While most clinical methods are the same for men and women, clinicians’ attitudes towards the application of some methods can be gendered. For example, one clinician recalled a time when a male patient inquired about the possibility of breast reconstruction; a suggestion they were seemingly amused and equally baffled by, and later described as “a bit ridiculous.” From this, I inferred that some clinicians perhaps consider the embodied breast cancer experience to be less important/meaningful for men, and disregard men’s related body image concerns; an oversight that could have important ramifications for men’s psychosocial health. Further, when discussing men’s requirements, another clinician suggested printing blue-coloured male-only resources for men; again, demonstrating their gendered thinking, overlooking men’s need for inclusion as opposed to further disparity. Both encounters, for me, illustrate how imperative it is to improve understandings about the wants and needs of men with breast cancer at every level, and how it cannot be assumed that clinicians simply know what is best.

In October 2015, I attended a football match at Southampton FC; this was a breast cancer awareness fixture, at which volunteers hand out information leaflets and collect donations for a breast cancer charity, and the home team plays in a pink strip. With the sporting event attracting a pre-dominantly male capacity crowd of 32,500 people in front of the world’s media, this seemed the perfect opportunity to raise awareness of breast cancer in men among the male population. However, the risk to men was never mentioned; not in the leaflet, and not in the talk delivered by the charity representative at the half-time interval, which focused on female statistics, and how men being more aware can help women to spot signs and symptoms sooner. Breast cancer in men was completely overlooked; total disconnection.
Having spent much of 2015 interviewing MEBs and listening to them discuss their need for recognition, the reality of this hit home to me after bearing witness to this marginalisation. I felt duty-bound to follow up the matter and contacted the charity and football club via their social media channels expressing my concerns; namely that breast cancer in men was disregarded, and that it was a wasted opportunity to potentially raise awareness among thousands of men (and women). The charity replied to say that they were due to focus on men at an upcoming event, but I felt this was tokenistic rather than inclusive, and that they missed the point I was trying to make about equality. I expected better from a dedicated breast cancer charity who I assumed would be more attentive to the breast cancer collective, but as with my experiences with the clinicians, it further highlighted why improving awareness about men’s needs is necessary across-the-board; re-emphasising the potential importance of the current research.

For me, being an ‘outsider’ had a number of personal benefits. First, cancer can be an emotional subject (Guillon, 2016); listening to the men’s account-giving and ‘seeing’ how they visualised the breast cancer experience was at times, despite my emotional distance, very moving; especially where men became visibly upset. So, I think the space between myself, the research topic and community served to protect my emotional well-being and helped me to better manage the emotional transference. Second, I think my distance from the illness and those affected by it was critical to my interpretation of the data, affording me the space to be more objective than I might have been had I personally experienced breast cancer. Though it is important to recognise the impact of my perspective on the data (Finlay, 2011), equally, my personal perspective is limited, helpfully restricting the extent to which the interpretations might have been influenced by my own views. Third, I consider that my distance has also maintained my interest throughout the research and beyond; my naïve curiosity and ‘not-
knowing’ position (Anderson & Gehart, 2007) encouraging me to want to learn more, not only about men and breast cancer but using visual research methods too, something I had no prior experience of before conducting this research.

What I think I underestimated at the beginning of the research process was the sense of responsibility I would feel as the researcher. Although from the outset I was conscious about the potential challenges facing me in researching a sensitive health topic (Dickson-Swift, James, Kippen & Liamputtong, 2007), being aware of the challenges and navigating one’s way through them are two entirely different things. For instance, I did not expect to form the bonds that I did with some of men I interviewed, and how this might influence my engagement with the research. Analysing the data took longer than expected, and I think this was partly due to my concerns about doing justice to the men and their data. Engaging in qualitative research is not only an exposing process for the participants, but the researcher too. I was very much aware of my role in the research and that my interpretations are not the only possible interpretations of the data. The findings presented are dependent on my position, the study sample and their meaning-making, and my response to these aspects accordingly. They were co-constructed in context, and another researcher may have drawn different interpretations (Finlay, 2003), since there is no right or wrong way to interpret qualitative findings. Despite this, in sharing my findings – especially with the study community – I have realised my vulnerability and concerns about how my writings might be received; yet, still, I recognise the importance of ‘owning one’s perspective’ as the author (Elliott et al., 1999).

9.9.2 Methodological reflections

Much of my methodological reflections centre around the application of the visual method, largely because having previously applied semi-structured interviewing and IPA analysis to other experiential studies with a health focus, the practice of employing these methods met
mostly with my expectations. The semi-structured approach to interviewing delivered as projected (see Chapter 4 – 4.3.1), affording the men space and time to ‘give voice’ on their terms, producing deeper insight, leading to richer data and interpretations (Sparkes & Smith, 2013). The schedule served as a useful guide, both for me and the participants, but was flexible enough so as to explore novel avenues of interest as they arose, as well as idiosyncrasies specific to the men’s individual experiences. Having the freedom to reorder and rephrase questions was useful, especially in the visual voice interviews, enabling participants to incorporate the photographs into the discussion as they saw fit; ceding control of the discussion to the participant, working to achieve a greater balance of power in the participant-researcher relationship, as is the intention in critical inquiries (Kindon et al., 2007).

Selected for its applicability to exploring under-examined phenomena and lived experience accounts of the meaning made about certain phenomena (Malhotra, 2015), performing IPA on the data achieved what this research set out to; a detailed understanding about how men experience breast cancer. The findings go beyond previous thematic analyses (e.g. Naymark, 2006; Donovan & Flynn, 2007) and Ackroyd’s (2016) IPA study of six US men, by offering expansive and revelatory interpretation from a different perspective. Being idiographic, the intention with IPA is always to focus on the particular rather than the general, and though the findings may demonstrate some transferability to other groups (e.g. women), generalisation was not the aim. What is presented is a particular perspective situated within a particular context (Smith et al., 2009). Also, as the men self-selected to participate in the research, it is important to recognise the relative bias, and that the sample is unlikely to be representative of all men’s related experiences.
Having only previously applied IPA to word-based data, using the method to analyse photographs was a new and stimulating experience for me but also challenging (see 9.4), given that there is little guidance for how best to perform IPA in this context. Analysing the verbal-visual data simultaneously made for lengthy transcripts, and initially I felt overwhelmed by the volume of data. Being transparent, consistent, thorough and organised in my approach though made the data manageable and enabled me to immerse myself without ‘drowning’ in the data (Smith et al., 2009). I also found that embedding the visuals into the transcripts maintained my interest where verbal accounts were similar as no two photographs were the same, or therefore the talk around those, ensuring that the uniqueness of the individual experience was not lost. Although IPA is traditionally employed with smaller samples, I maintain that the method was a suitable selection based on the study’s primary question and aims and consider that I have explored each man’s account in sufficient depth and detail that the men can recognise their individual ‘voices’ in my discussions about the data. The interpretations presented are grounded in examples, and coherence is demonstrated (Elliott et al., 1999) through my use of schematic representations, thematic maps and tables; enabling the reader to follow the analytic process and ascertain how I identified the superordinate masculinities and corresponding subthemes.

When thinking initially about the photographic method, I had predominantly – almost exclusively – given thought to what the men would photograph; first, whether they would be able to express their breast cancer experiences photographically, and second, whether they could do so without breaching ethics. Thus, in focusing on what the men would capture on camera, I had overlooked the importance of photographs that were not taken; be that for personal or ethical reasons, and how insightful this might be. Without the corresponding visual accounts – possibly still even with this material – uncaptured experiences potentially
remain untold. Fortunately, I realised this oversight during my first interview, following a discussion with the participant who, as the first to take part, had prior agreed to be a ‘research partner’ (see Chapter 4 – 4.3.1); advising on the content and phrasing of the questions forming the interview schedule and the experience of practicing visual voice. In keeping with the community engagement aspect of the research, the thinking behind this was that it would highlight potential ‘red flags’ at an early stage, so that any issues which might cause men undue stress or discomfort, or deter participation, could be addressed. In giving his feedback, the participant said “can I tell you about what’s missing? Because I think maybe that’s significant”. He explained how he was unable to express some aspects photographically, due either to ethical restrictions or because he was providing a retrospective account and could not generate certain material, e.g. a photograph of himself whilst undergoing treatment, having purposefully decided not to record any at the time because “I didn’t feel like I was me”. I then recognised the potential for meaning in what is unphotographed, especially material that is purposefully omitted from participants account-giving, as they exercise their right to silence their own ‘voice’; which in itself is interesting. From then on, I explicitly asked participants “is there anything you would like to have photographed but didn’t for any reason?” While the majority said ‘no’, in some cases, this did prompt men to discuss aspects which may have otherwise remained unsaid.

Personally, as the researcher, I enjoyed engaging with the photographic method; from learning about how participants conceived and created their images, to their meanings and what they represent, and how I then interpreted them. Incorporating images within the transcripts ensured the data was well organised, and also made the analysis more manageable, providing welcome breaks from the vast amount of textual data. It was interesting to see how the men approached the photo task in their individual ways, and also how they conveyed
similar concepts using different visuals. I was surprised by how abstract some of the men’s photographs were, and equally by how many chose to photograph their bodies given the known effects of breast cancer on men’s body image (e.g. Pituskin et al., 2007; France et al., 2000), and the concerns that some expressed (see 9.4). The photographs unequivocally aided the men’s explanations and sense-making, especially hard-to-discuss topics, and prompted them to engage more with their emotions; generating deeper richer insight. Having never previously employed a visual approach, I had very few expectations; that said, using this method far exceeded what I hoped it would achieve in terms of data quality.

In addition to documenting my own methodological reflections, given that this is a CHP inquiry, it is equally important to share also the reflections of the study participants. By and large, those who participated in visual voice found it to be an enjoyable and worthwhile exercise, causing them to think about their breast cancer experiences in new and interesting ways. Fortuitously, several of the participants were keen photographers, and although unfamiliar with the research method, were well-versed on taking photographs. When asked to critique the method, generally the men spoke favourably about the integrated approach; some describing it as “cathartic” (Jonathon), others commenting that it gave “more poignancy” (Tom) to and enhanced their account-giving. Below is a selection of positive comments offered by some of the men about the visual voice method:

“I think the images made me study it a little bit more which is good... it was a good way of explaining things, I was a bit sceptical at first but I think it helps” (Bill)

“I enjoyed the process it’s nice a bit like going over an old photograph album remembering things that you’ve done in the past (...) normally photograph albums are about remembering lovely holidays and things like that but sometimes it’s good to think back to tougher times too” (Glenn)
“It’s one thing telling people about it but if you’ve got the images as well then it gives another perspective” (Neil)

“I think it’s interesting one or two things ‘ave come up while we’ve been talkin’ like it’s clicked back into me memory a little bit yeah... I found it both really challenging to come up wi’ something I thought was relevant and quite enjoyable to look back on it again in this way” (Ed)

Reflecting on these men’s reflections, my interpretation is that most men recognised the value of the methodological approach and considered that they had benefitted psychologically from participating in visual voice. However, not all men shared the same enthusiasm for the photographic method: “I’m not one for photos to be honest wi’ ya” (Douglas), “I haven’t the time for that” (Charles); one specifically not in the context in which it was employed:

“A photograph is just a captured moment in time nothing more and cancer is something which you’re living with all the time so it’s always moving... I’m not against it I just don’t think a static image captures anything that’s why I’ve used paintings” (Jonathon)

Jonathon was the last of the 31-man sample to be interviewed; had he have been the first then, despite liaising with the research partner, I may have seriously doubted the suitability of applying the photographic method to studying chronic illness and masculinity, since both are shifting and fluid concepts (Temple, McLeod, Gallinger & Wright, 2001; Connell, 2000), in contrast to photographs which are unchangeable. Despite receiving this feedback so late on into the research process, I still feel that it has benefitted the research, and also future related research; encouraging me to think about alternative visual methods that might be applied. For instance, employing video diaries is one possibility, though whether affected men would be as
willing to engage with videography remains to be seen. Some men felt that photographs were too identifying and exposing, and video recordings are arguably even more so. Therefore, while videography may overcome some of the limitations associated with photographs, it has its own constraints, including additional legal and ethical restrictions (Wiles, Prosser, Bagnoli, Clark, Davies, Holland et al., 2008).

9.10 Concluding remarks

Through exploring, in-depth, the lived experiences and meaning-making of men affected by breast cancer, this research programme has aimed to produce an original and innovative contribution, to advance understandings about this relatively rare and poorly understood illness in men. Guided by the extant literature base – albeit limited – which positions breast cancer in men as a critical health issue with complex ramifications for those affected; the research, embedded in a critical health psychology framework, has employed a multi-method approach and a multi-faceted recruitment strategy, that sought to address some of the limitations of earlier inquiries. Specifically, it aimed to ‘give voice’ to what remains an under-researched and marginalised male population, and to offer recommendations for improving the experiences of future men diagnosed with breast cancer.

This thesis has integrated and triangulated the findings from two study phases. The first component has comprised a qualitative synthesis of nine existing international studies exploring men’s breast cancer experiences. Findings from this synthesis have then been used to inform the second component: A new, multi-method phenomenological exploration of men’s verbal and visual breast cancer accounts. Through this research the on-going marginalisation of men across the breast cancer trajectory, and how this influences men’s experiences of, and adjustment to the illness, has been revealed. Findings from the qualitative
synthesis have suggested how current approaches to breast cancer care and advocacy serve to isolate men, potentially alienating and emasculating them; while patient management practices and informational resources unequivocally marginalise men. Findings from the new inquiry have corroborated those from earlier studies, further illuminating the difficulties men encounter, and some of their coping strategies. Specifically, three superordinate masculinities were identified: ‘threatened and exposed’, ‘protected and asserted’ and ‘reconsidered and reconfigured’. A schematic representation has been developed and presented to illustrate how these interconnected masculinities are encountered, performed and utilised by men, from pre-diagnosis through treatment and beyond; as they manage, make sense of and live through breast cancer.

How and why men encounter/perform these different masculinities at different points in time across the breast cancer trajectory, and how this aids men’s adjustment to illness and life beyond the diagnosis, has been considered in view of the critical framework that the research aimed to embed itself within. On the whole, the research succeeded in delivering a CHP study; giving voice to members of a marginalised and minority community, affording participants greater choice and control over their participation, and upholding high ethical standards. However, the researcher recognises that not all aspects of CHP were fully achieved; for example, the idea of involving a co-researcher from the affected community, and the study was not very successful in its aim to represent the diversity of the population of men who have experienced breast cancer. Further, although overall the integrated methodological approach employed was both suitable and fruitful in this research context, insofar as achieving the research goals and producing rich data; the researcher acknowledges that tensions exist between the combined methodologies, particularly between the individualism and critical realism of IPA, and the community and more realist position of PR.
Nevertheless, the research demonstrates that methodological synergy is both possible and advantageous.

Finally, the outcomes of this research programme suggest that future research is needed targeting men from BAME and other minority groups who have experienced breast cancer; as well as greater patient and public involvement in both research and clinical decision-making. A number of ideas for further study are presented. The researcher has identified several potential avenues for future research, but also recognises the need for greater collaboration with and input from affected men going forward. Further, based on the findings of this two-part inquiry, several recommendations are offered for improving future breast cancer care, practices, support services, and policies. These recommendations include; redressing clinical settings to appear more gender and culturally neutral to help foster greater inclusivity for all patients; engaging men in clinical studies; ensuring that men have a ‘voice’ and are more visible in resources aimed at patients and within the wider breast cancer community; and policymakers collaborating with affected men to produce policy documents.
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Appendices

Appendix A

Interview Schedule

Can you tell me a bit about yourself ...?
- about you, your ‘family’ set-up
- where you live, and who with
- occupation

Before you experienced breast cancer yourself, what was your knowledge or awareness about the illness in men?
- How did you understand breast cancer beforehand?
- Were you aware that men could develop breast cancer?
- Family history?

How do you think breast cancer in men is viewed by people generally?
- How do you think these perceptions/understandings impact on male patients/survivors?
- What have your experiences been when talking about your breast cancer?
  - Responses/reactions – laypeople, specifically other men – professionals
- How have your own views about breast cancer changed since being diagnosed yourself?

Can you explain to me what happened/what you experienced prior to being diagnosed with breast cancer?
- What signs, symptoms did you experience? How did you respond to these?
- How quickly did you seek care/ medical attention?

Talk me through the diagnosis process...
- What was involved?
- Duration of diagnosis

How did your breast cancer diagnosis affect you?
- What were your initial thoughts? How did you feel? Who did you tell?
- Impact on your partner/family/significant others

After you received your diagnosis, what happened next?
- What was advised?
- Course of action

What are your views on/experiences of the methods used to treat breast cancer?
- Can you describe to me the treatment(s) you’ve had? How do/did you feel about these?
- What (if any) expectations did you have pre-treatment?
- Knowledge about/ experiences of follow-up procedures
What would you say are the main challenges and frustrations of living as a man with breast cancer?
- How does it affect your everyday life?
- To what extent do you think male patients experience similar or different challenges/frustrations to female patients? How? Why?

How have you coped with your breast cancer experience?
- Physically, emotionally, socially…
- What has hasn’t helped?
- Have you explored the use of complementary/alternative medicines?

How has having breast cancer affected relationships in your life?
- Partner, family, friends, colleagues
- Male relationships

What has been your experience in terms of professional care and support?
- What support is there for breast cancer patients? For survivors? For families affected?
  - physical and psychological
  - pre-treatment, during treatment and aftercare
- NHS-based Vs. Non-NHS support, e.g. Charities – similarities/differences in support

Have you/ would you attend a breast cancer support group?
- Yes/no, why/why not?
- In-person, Online – preference?
- Have you spoken/ met with other men who have/ have had breast cancer?
  - If not, would you have welcomed the opportunity to do so?

What are your views regarding educational/informational materials that are available to breast cancer patients?
- What content is covered/ included?
- Are they relevant to and adequate for male patients? Do they meet with men’s needs?
- Are these resources easily accessible, and readily-understood?
- How could informational materials be improved from your perspective?

How has your breast cancer experience affected the way that you see yourself, your life or the world?
- Your body image? Your sexuality?
- How do you feel about the scarring on your body?
- Your participation in work and leisure activities – how has this been affected?

What do you think about current breast cancer campaigns?
- Which campaigns are you aware of/ do you know about?
- Thoughts on the images, language and ‘the message’ in existing campaigns
- What could be done to increase knowledge and awareness of male breast cancer?

Should we encourage men to be more ‘breast aware’ and to engage in preventive health practices, such as breast self-examination?
- Did you and do you practice self-examination?
- Would you have attended screening had it been offered to you?
- Would you encourage male relatives/friends to self-examine and to attend screening?
What advice might you offer to other men who are diagnosed with breast cancer?

Have there been any positive elements that have emerged from your breast cancer experience?

Are there any other important elements of your breast cancer experience that we’ve not had the chance to discuss?
Appendix B
‘Photovoice’ Interview Prompts

Photograph – Prompts

• Tell me about image X
  o Describe to me what’s going on in the photograph
  o Why did you select this particular photograph?
  o What does this image represent?
  o How does the image make you feel?
  o How does the image illustrate your breast cancer experience?