

**“It’s All About Balance...”**  
**Women’s Experience of Having One Breast**

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## CANDIDATE DECLARATION

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<p>I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.</p> <p>I confirm that the decision to submit this thesis is my own.</p> <p>I confirm that except where explicitly stated, the work has not been submitted for another academic award.</p> <p>I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.</p> <div><div>Signed:</div><div>Date:</div></div>	

## **Preface**

Breast cancer is the most common cancer in women in England and Wales, with a lifetime prevalence of one in eight women (National Institute of Health and Care Excellence, 2011). All women are at risk; 80-90% of women who are diagnosed have no pre-existing familial or genetic risk (Port, 2015).

Breast cancer is categorised into four stages (stage 1 to 4) depending upon its development, which includes whether it is invasive (the potential for the cancer to spread), the size of the tumour and the number of lymph nodes involved (Greener, 2015). Cancer staging helps determine prognosis. Treatment options are determined by the stage of cancer at diagnosis, ranging from lumpectomy or partial mastectomy (the cancer is removed whilst restoring healthy breast tissue) through to mastectomy (removal of the breast). Early stage breast cancer (stage 0) is called Ductal Carcinoma in Situ (DCIS) and is associated with the greatest degree of survival (NICE, 2002). Four in ten women diagnosed with breast cancer undergo a mastectomy as their primary therapeutic procedure (Jeevan et al., 2014). Additional therapies are used to treat the breast cancer alongside surgical procedures, these include hormone treatments, chemotherapy or radiotherapy (NICE, 2002).

Breast care services are delivered by multidisciplinary teams which comprise breast care Nurses, Pathologists, Radiologists, Oncologists and a Care Coordinator. The team are required to work closely alongside other professionals who would be considered 'extended' members of the immediate team, including Clinical Psychologists (Rainsbury & Willett, 2012).

The role of Clinical Psychologists working within oncology services is recognised by the Division of Clinical Psychology, Faculty for Oncology and Palliative Care. This division aims to promote high standards of care through the application of psychological interventions to people experiencing emotional distress in response to cancer. Psychologists predominate in contributing to psycho-oncology as a discipline and in the delivery of psychosocial research within oncology (Hewitt, Herdman & Holland, 2004).

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## Definition of Terms

<b>Adjuvant Therapy</b>	Treatments that are used in addition to surgery, for example, chemotherapy and radiation.
<b>Autologous Reconstruction</b>	A type of breast reconstruction that involves having muscle tissue from one part of the body (usually the abdominals, back or buttocks) surgically removed to form a breast mound.
<b>Bilateral Mastectomy</b>	The removal of both breasts during the same operation. This is sometimes performed for the treatment of a unilateral breast cancer when a woman has requested to have a contralateral prophylactic mastectomy performed at the same time.
<b>Bilateral Prophylactic Mastectomy</b>	The removal of both breasts to reduce the risk of breast cancer prior to having a breast cancer diagnosis. This is usually performed on women who are at high risk of developing breast cancer and who likely carry a genetic susceptibility.
<b>Bilateral Breast Reconstruction</b>	When both breasts are reconstructed following a bilateral mastectomy. A bilateral reconstruction can be performed during the same operation as a bilateral mastectomy, or after a delayed period of time.
<b>BRCA 1 and BRCA 2</b>	Breast Cancer Gene 1 & 2. When mutated, these genes are associated with an increased risk (up to 80%) of developing breast cancer.
<b>Breast Conservation</b>	The removal of the affected breast tissue whilst restoring the remaining healthy breast tissue.
<b>Contralateral Prophylactic Mastectomy</b>	The removal of the opposite healthy breast after having a unilateral breast cancer. This procedure is performed to reduce the risk of a future breast cancer in the opposite breast.
<b>DCIS – Ductal Carcinoma-in-Situ</b>	Non-invasive abnormal cells that are confined to the milk duct. These cells sometimes have the potential to develop into a malignant cancer.

<b>Elective Breast Surgery</b>	Surgery that is pre-planned and is not for the treatment of breast cancer. This study refers to elective surgery as being either breast reconstruction or contralateral prophylactic mastectomy.
<b>Partial Mastectomy</b>	This is the same as having a 'breast conservation' procedure.
<b>Prosthesis</b>	An external breast mould, usually made from silicone that women can use to create a breast mound within their bra.
<b>Stage/Staging</b>	The stages in which cancer is graded based on tumour size, the number of lymph nodes involved and the presence or absence of distant metastatic disease. The higher the stage, the greater the size of the tumour and likelihood of metastasis.
<b>Surveillance</b>	This is the term given to the process of having a breast monitored by imaging technology, for example, mammograms and MRI.
<b>Therapeutic Unilateral Mastectomy</b>	A mastectomy performed for the treatment of breast cancer in one breast.
<b>TRAM Flap Reconstruction</b>	A type of autologous reconstruction which refers to the name of the muscle that is being used to create the breast mound - Transverse Rectus Abdominis, a muscle in the lower abdomen.
<b>Unilateral Breast Cancer</b>	A breast cancer confined to one breast.

## **Thesis Abstract**

The aim of this thesis is to explore the experiences of women who have one breast, or who have the potential to be left with one breast, following a mastectomy for the treatment of breast cancer.

Paper 1 is a qualitative literature review that explores women's decisions to have a breast reconstruction or a contralateral prophylactic mastectomy (CPM) following a diagnosis of breast cancer. Through their decisions to have elective surgery, women avoid the possibility of having to manage a life with one breast. Twelve papers were critically appraised and synthesised using a thematic analysis. Women processed their decisions in similar ways irrespective of the surgical procedure. A breast reconstruction or CPM enabled women to move on from having cancer.

Paper 2 is an empirical research paper that explores the experiences of seven women who have one breast after having a mastectomy. Women were interviewed and transcripts were analysed using Interpretative Phenomenological Analysis. After having a mastectomy, breasts were experienced to lose their meaning in a way that a reconstructed breast could not replace. Women described their experiences of using a breast prosthesis which served to restore women's physical and social selves. Women focused on aspects of their lives which they valued over the loss of their breast. This enabled them to move on from cancer without having a breast reconstruction.

Paper 3 provides a reflective commentary on Papers 1 and 2 which describes the ethical and methodological processes of conducting this research. The researcher reflects on her own position within a breast cancer culture.

**Word count: 257**

## Paper 1

### Contralateral Prophylactic Mastectomy and Reconstructive Breast Surgery: Pathways to Recovery?



Word Count: 7693

## **Journal Submission Details**

This paper has been written with the aim of being submitted to the Journal 'Psycho-Oncology', selected due to its focus on psychological aspects of cancer and its multidisciplinary interest. This journal is interested in research articles relevant to clinical decision-making within oncology. The journal prescribes a maximum of 6000 words for research papers (see Appendix A). The word count of Paper 1 will be reduced by changing the reference style from the American Psychological Association (6<sup>th</sup> Edition) to 'Vancouver' referencing as well as removing some definition of terms and reducing the content of Table 2.

## **Abstract**

**Objective.** To explore the decision-making processes used by women who elect to have a contralateral prophylactic mastectomy (CPM) or a breast reconstruction, following a diagnosis of unilateral breast cancer.

**Methods.** A systematic approach to a literature review was conducted to identify qualitative research specific to women's experiences of decision-making. A thematic synthesis was performed.

**Results.** Twelve papers were included for review. A decision-making process model was developed based on women's experiences of choosing CPM or reconstruction. Women experienced their life being on 'hold' following a diagnosis of breast cancer, causing them to negotiate ways of moving on from cancer. This involved assimilating information about their surgical options as well as making meaning from their decision. Other women considered the impact of their decision on their future well-being and their fear of cancer returning. Decisions were determined by the extent to which surgical methods, health professionals and surveillance methods could be trusted to effectively meet their physical and emotional needs.

**Conclusions.** Women processed their decisions in similar ways irrespective of their elective surgical choice. The decision-making process model was found to be situated against a contextual paradox in which women's decisions have been understood distinctly based on the surgical method. Women should be offered psychological support wherever necessary to facilitate their decision, irrespective of the surgical method they are electing.

## **Background**

### **Contralateral prophylactic mastectomy**

Contralateral prophylactic mastectomy (CPM) is an elective surgical procedure that involves the removal of the opposite healthy breast for the prevention of breast cancer recurrence (Nekhlyudov et al., 2005). CPM has a significant risk-reducing benefit for women who carry a genetic risk for breast cancer, for example, the Breast Cancer Gene, BRCA 1 or 2 (Schwartz, 2005). Over the last decade (Wood, 2009), women have been increasingly electing to have a CPM, both in the U.S. and in England (Neuburger, MacNeill, Jeevan, van der Meulen & Cromwell, 2013). This rise is accounted for by women across all risk groups, including women who do not carry a high risk of developing contralateral breast cancer, and where alternative, less extensive and equally effective surgery is available (Tuttle, Habermann, Grund, Morris & Virnig, 2007). There are conflicting findings regarding the overall survival benefit of having a CPM in women who are not at high risk (Angelos et al., 2015) and there is limited guidance for when it should be considered (see Giuliano et al., 2007). For this reason, CPM has been deemed by some as being a controversial procedure (Ager, Butow, Jansen, Phillips & Porter, 2016).

Women can elect to have a CPM at the same time as their therapeutic mastectomy (called a 'bilateral mastectomy') or following a delay. The biggest contributing factors for wanting a CPM are women's fear of developing a contralateral breast cancer, irrespective of their risk (Basu, Barr, Ross & Evans, 2015; Buchanan et al., 2016) and the desire for breast symmetry (Buchanan et al., 2016). Women who elect to have a CPM are younger in age, are Caucasian ethnicity (Tuttle et al., 2007) and have received higher education (Agarwal et al., 2015; Soran et al., 2015; Yi et al., 2010) than women not electing CPM.

### **Breast reconstruction surgery**

Similarly to CPM, breast reconstruction is an elective surgery that can be performed either at the same time as having a therapeutic mastectomy (immediate reconstruction), or some time following surgery (delayed



reconstruction). It can also be performed following a bilateral mastectomy, called a 'bilateral reconstruction'. Breast reconstruction is performed to restore the breast shape, which can be achieved either by using the person's own muscle tissue (called autologous reconstruction) or using implant methods (D'Souza, Darmanin & Fedorowicz, 2011). Some women choose not to have additional surgery following their mastectomy and may decide to wear a breast prosthesis. In the U.K., the National Institute for Health and Care Excellence (NICE, 2009) recommend that breast reconstructive surgery is offered to all eligible women.

Similar social demographic factors associated with CPM are also associated with reconstruction, such as being younger in age (Alderman et al., 2011; Ng et al., 2014), and having a higher level of education (Fallbjörk, Karlsson, Salander & Rasmussen, 2010). Breast reconstruction can help to reduce the psychological impact of losing a breast as well as to achieve normality (Denford, Harcourt, Rubin & Pusic, 2011; Mckean, Newman & Adair, 2013), restore body image (Amsellem, Ahmed, Haskins, Weiss & Buzaglo, 2011) and femininity (Reaby, 1997). Reconstruction also avoids the inconvenience of wearing an external breast prosthesis (Crompvoets, 2003; Harcourt & Rumsey, 2004).

### **Decision-making and elective surgery**

The timing and method of reconstruction intersects with the decision to have a CPM (Angelos et al., 2015; Buchanan et al., 2016; Soran et al., 2015); Ashfaq et al. (2014) found women were three times more likely to undergo CPM if immediate reconstruction was offered to them. To improve breast symmetry, Angelos et al. (2015) found women were more likely to elect a bilateral mastectomy and reconstruction if offered only a silicone implant method.

### ***The role of Clinical Psychologists***

Deciding to have elective surgery is a complex issue, especially given the numerous options available and the limited time in which these decisions are often made (Rainsbury & Willett, 2014). To alleviate these difficulties, the National Health Service promotes a model of 'shared decision-making'

between patients and clinicians (Coulter & Collins, 2011). Clinical Psychologists have the necessary skills to support women's decision-making through developing collaborative person-centred assessments and to formulate a person's needs (British Psychological Society, BPS, 2008). Current 'best-practice' guidelines recommend Psychologists as a source of support for women electing reconstruction (Rainsbury & Willett, 2014) and CPM (Basu, Ross, Evans & Barr, 2015).

Clinical Psychologists apply psychological theory to clinical practice, which can help to understand the impact of mood on clinical decision-making. For instance, anxious individuals are more likely to have an attentional-bias towards threat (Beck & Clark, 1997), which could lead to the development of maladaptive health beliefs and subsequent health-related behaviours (Ajzen, 1991). This is important given that women can experience high levels of anxiety and depression prior to and following a mastectomy (Harcourt & Rumsey, 2001; NICE, 2002). Clinical Psychologists are also required to be aware of the impact that psychological distress can have on a woman's capacity to give informed consent to have a surgical procedure (BPS, 2009).

Psychologists have contributed towards the development of a decision-making tool (for example, Sherman, Harcourt, Lam, Shaw & Boyages, 2014), which have been found to provide patients with greater knowledge leading to less decisional-conflict (O'Connor et al., 1999). This is an important issue given that some women have expressed regret over their decision to have CPM (Ager et al, 2016), and reconstruction (Sheehan, Sherman, Lam & Boyages, 2008). Currently, there is no published tool supporting the decision to undergo CPM (Zdenkowski, Butow, Tesson & Boyle, 2016).

## **Summary**

Current research indicates that whilst there are some unique factors, there is also a degree of overlap between the variables that predict women's decisions to have reconstruction or CPM. Further research is required to explore women's experiences of choosing CPM and reconstruction, given that there are likely to be "other variables" driving this decision (Yi et al., 2010). This

information will aid Clinical Psychologists in their role of supporting women to make clinically-informed decisions.

## **Literature review**

Factors that influence women's decisions to have a CPM or a reconstruction have mostly been explored separately. Consequently, tools to aid decision-making do not combine choices for reconstruction and CPM simultaneously. However, evidence suggests that decisions for wanting a CPM may be influenced by the type of reconstruction method available (Ashfaq et al., 2014). Yet, whilst breast reconstruction in the U.K. is encouraged, the use of CPM is not. Our current knowledge of decision-making is based largely on the findings of quantitative studies that do not reveal the processes of how decisions are made (Ager et al., 2016). Also, demographic factors that appear to be consistently related to the decision to undergo elective surgeries are not necessarily factors that feature within the decision-making process (Lee et al., 2011). No previous review has explored the processes that underlie the decisions to have elective surgery. This review, therefore, sets out to meet the following aims:

## **Aims**

1. To identify the processes that underpin the decision to have a breast reconstruction or a CPM in women who are not considered to be at high risk of developing contralateral breast cancer;
2. To identify converging and diverging themes across decision-making processes for reconstruction and CPM.

## **Method**

A qualitative literature review was carried out to explore women's experiences of decision-making for reconstructive surgery and contralateral prophylactic mastectomy.

## **Search Strategy**

The search was driven by the Phenomenon of interest, Intervention, Context and Outcome (PICO) model adapted for qualitative research (Ring, Ritchie,

Mandava & Jepson, 2011; see Table 1). Keywords were developed as driven by the aims of the review such as: 'Mastectomy', 'Breast Reconstruction', 'Contralateral Prophylactic Mastectomy' and 'Decision-making', while excluding 'BRCA 1 & 2'. The same terms were used in each database and were searched either by abstract or topic. Keywords were truncated to include a variation of terms and then combined with other keywords using the "OR" "AND" and "NOT" Boolean strategy (see Appendix B). Studies published prior to 1985 were excluded due to the modernisation of reconstruction techniques during the 1980s, namely the development of the Becker Expander which improved operation times and breast symmetry (Camilleri, Malata, Stavrianos & McLean, 1996; Uroskie & Colen, 2004).

A systematic search was performed on the 14<sup>th</sup> December 2016 using 11 electronic databases. EBSCOhost was used to search the following databases: Medline, Academic Search Complete, SPORTDiscus with Full Text, CINAHL plus with full text, PsychINFO, Amed, and psychARTICLES. Web of Science, and the Cochrane Library were searched individually. All databases were selected based on their focus on health, psychology and medicine.

**Table 1.***Inclusion and Exclusion Criteria*

<b>Strategy</b>	<b>Inclusion</b>	<b>Exclusion</b>
<b>Phenomenon of interest</b>	Women who have had a unilateral breast cancer	Women with a known genetic breast cancer risk  Bilateral breast cancer
<b>Intervention</b>	Breast reconstruction (including immediate and delayed)  Contralateral prophylactic mastectomy  Bilateral mastectomy	Bilateral prophylactic mastectomy  Contralateral mastectomy due to known BRCA 1 & 2  Partial mastectomy/breast conservation
<b>Context</b>	Oncology  Research post-1985	Research pre-1985
<b>Outcome</b>	Exploring decision-making is the primary aim of the research  Experiences relating to decision-making	Partner experiences alone  Surgeon perspectives alone
<b>Study Design</b>	Qualitative research  Peer reviewed  Written in English	Review papers  Quantitative methods  Mixed methods  Case studies

**Results**

Irrelevant health-related topics were excluded from the Web of Science search (See Appendix C) and an English-language limiter was applied to all three databases. Duplicates were removed from the results of individual databases (N= 412 in total). A total of 2158 references were transferred to RefWorks where duplicates across all databases were removed (a total of 586; see Figure 1).

### **Screening procedure**

Titles and abstracts of the remaining 1572 articles were screened against the inclusion and exclusion criteria. Articles not meeting this criteria (n= 1542) were excluded and crudely categorised (see Appendix D). Full texts of the remaining 30 articles were screened; 10 were excluded based on not meeting the inclusion and exclusion criteria, leaving 20 articles to be further assessed. Another 8 articles were excluded due to there being a less-specific focus on decision-making and in one case, not meeting the CASP quality criteria (see Appendix E for further details). Twelve articles were included for review. The search results are presented in Figure 1 which illustrates the PRISMA diagram (Preferred Reporting Items for Systematic Reviews and Meta-analysis; Moher, Liberati, Tetzlaff & Altman, 2009). Articles that presented ambiguity in respect to the inclusion criteria were also screened by the author's clinical supervisor. A discussion was had until agreement was reached.

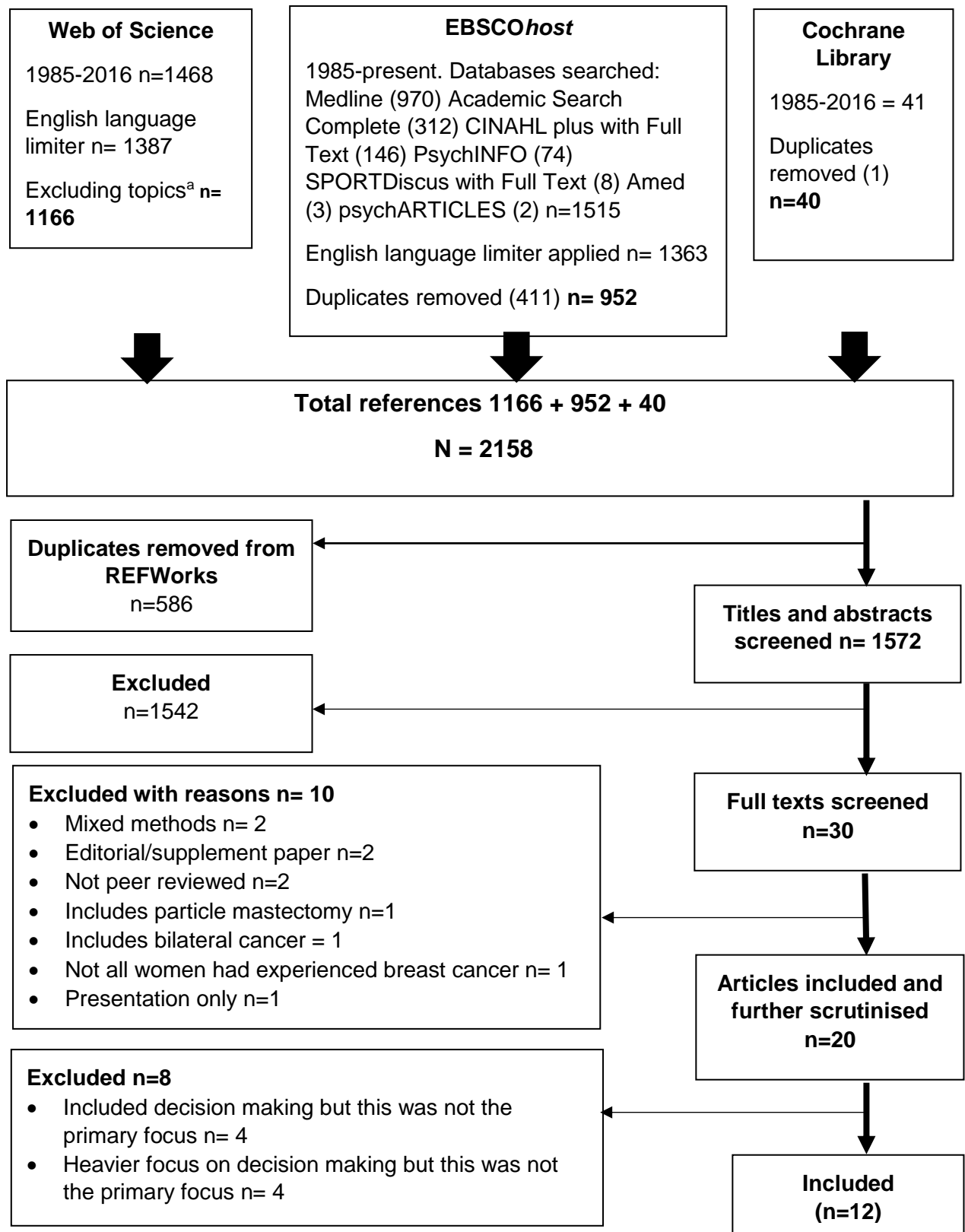


Figure 1. PRISMA Diagram of the Literature Search Strategy

<sup>a</sup>See Appendix C

### **Quality criteria**

A Critical Appraisal Skills Programme tool (CASP, 2014) specific for evaluating qualitative research was used to critique each paper and articles were scrutinised against 10 different criteria. A CASP framework was selected based on its multidimensional approach to evaluation, focusing on content, method and the process of producing qualitative data. This was completed by the author and a second reviewer. Each criterion was scored between 0-2 (0= criterion not fulfilled, 1= partially fulfilled, 2= fully fulfilled; see Appendix F) to give a total score out of 20 for each article. Articles were scored independently of one another; differences in the scores were resolved by consensus and given a final score which was converted to a percentage (see Table 2).

### **Data extraction**

Data were extracted from the included articles, which included: the title, aims, sample size, method and clinical relevance (see Table 2). These categories were selected to provide a clear overview of each study in terms of how the authors achieved their findings and their clinical relevance. Participant characteristics were also extracted (see Appendix G) including: cancer stage, age, time since surgery, surgery type, marital status, education and ethnicity. These categories were selected to provide an overview of how participant characteristics may have influenced the findings of each study. The extracted data was used to guide the thematic synthesis.



**Table 2.***Data Extraction of Studies Exploring Women's Experiences of Decision-Making for Breast Reconstruction and CPM*

Author/ Year	Quality score (%)	Size	Title	Aims	Method	Clinical Relevance
Beesley, Holcombe & Salmon, 2013  U.K.	80	60 patients and 4 surgeons	Risk, worry and cosmesis in decision making for risk reducing contralateral mastectomy.	To explore decision- making for CPM in a single centre.	Case note research using qualitative methods.  Mixed prospective and retrospective design.	A lack of guidelines for CPM surgery contributes to the inconsistency of the decisions made both by patients and surgeons. Further evidence that CPM can effectively reduce worry and improve cosmesis is needed.
Begum, Grunfeld, Ho- Asjoe & Farhadi, 2011  U.K.	75	21	An exploration of patient decision-making for autologous breast reconstructive surgery following a mastectomy.	To explore reasons for having autologous breast reconstruction (including immediate and delayed).	Framework analysis using semi-structured interviews (including face to face and telephone interviews)  Retrospective design.	Women are not always offered a choice regarding the timing of surgery. Information should be tailored to the needs of the individual. This will ensure women can make an informed decision.

Author/ Year	Quality score (%)	Size	Title	Aims	Method	Clinical Relevance
Boehmer, Linde & Freund, 2007  U.S.	60	15	Breast reconstruction following mastectomy for breast cancer: The decisions of sexual minority women.	To explore the issues that lesbian and bisexual women and their support persons' experience when deciding to have a breast reconstruction.	A retrospective design using grounded theory and semi-structured interviews with n=8 women who had undergone reconstruction and n=7 women who chose against it.	This study challenges the focus of current research on heterosexual identity and heterosexual partner experiences. Partners described not being well-informed about the risks of surgery.
Covelli, Baxter, Fitch, McCready & Wright, 2015  Canada	80	29	'Taking control of cancer': Understanding women's choice for mastectomy.	To explore women's decision-making for mastectomy (either unilateral mastectomy or CPM) for the treatment of early stage breast cancer.	Grounded theory using semi-structured interviews of women who either had mastectomy (n=15) or mastectomy and CPM (n=16).  Retrospective design.	The study highlights the need for health care providers to consider the influence of fear on decision-making for bilateral mastectomy for early stage breast cancer.
Harcourt & Rumsey, 2004  U.K.	90	93	Mastectomy patients' decision-making for or against immediate breast reconstruction.	To explore the process that women make when deciding to have breast reconstruction and to explore the impact of surgery during the first post-operative year.	Thematic analysis used with semi-structured interviews prior to, 6 and 12 months' post-surgery with women who had elected for (n=37) or against (n=56) immediate reconstruction.  Retrospective design.	The authors distinguished between different decision-making patterns which could be used to identify women who require psychological support before surgery.

Author/ Year	Quality score (%)	Size	Title	Aims	Method	Clinical Relevance
Jerome- D'Emilia, Suplee, Boiler & D'Emilia, 2015  U.S.	95	23	A woman's decision to choose bilateral mastectomy.	To explore the reasons why women choose CPM for the treatment of unilateral breast cancer regardless of their cancer stage.	Thematic analysis. Semi- structured interviews with women who had undergone a bilateral mastectomy followed by bilateral reconstruction.  Retrospective design.	The authors recognised how women are offered multiple surgical options and that these should be offered and selected based on: the personal preferences of the patient, evidence based practice and with information regarding the risk and benefits of surgery.
Lee, Hultman & Sepucha, 2010  U.S.	50	65	What are patients' goals and concerns about breast reconstruction after mastectomy?	To identify patient's preferences and concerns when considering reconstruction.	A thematic approach. Focus groups and interviews with women who had either undergone reconstruction or not.  Retrospective design.	The authors highlight the importance of medical professionals in supporting the patient's decision and to ensure a shared-approach to decision- making is offered.
Neill, Amstrong & Burnett, 1998  U.S.	75	11	Choosing reconstruction after mastectomy: a qualitative study.	To explore how decisions to have a breast reconstruction are made.	Qualitative design. Semi- structured interviews with women who had undergone a breast reconstruction.  Retrospective design.	The authors identified that information seeking may serve as a coping strategy. Professionals need to determine how much information is needed to support a woman's decision.

Author/ Year	Quality score (%)	Size	Title	Aims	Method	Clinical Relevance
Reaby, 1998  Australia	60	95	Breast restoration decision making: enhancing the process.	To explore breast restoration decision-making patterns made by women who have had a mastectomy.	Theoretically driven qualitative enquiry using semi-structured interviews with 31 women with breast reconstruction and 64 without.  Retrospective design.	A decision-making tool to aid decisions for reconstruction was developed. Medical staff need to evaluate whether women have adequate information or resources to make an informed decision.
Rendle, Halley, May & Frosch, 2015  U.S.	70	9	Redefining risk and benefit: understanding the decision to undergo contralateral prophylactic mastectomy.	To explore decision-making in women electing CPM with no known BRCA mutation.	Grounded theory. Semi-structured interviews with nine newly diagnosed women with unilateral breast cancer.  Prospective and retrospective.	Numerical calculations of risk may not be the most effective way to engage with women's subjective risk-assessment of their cancer returning. Women need to be given time to think about their decision and that methods for surveillance on the contralateral breast should be explored further.
Rubin, Chavez, Alderman & Pusic, 2013  U.S.	95	27	"Use what God has given me": Difference and disparity in breast reconstruction.	To explore breast reconstruction decision making amongst African American women.	Grounded theory. Semi-structured interviews with 23 women who had reconstruction and four women who had not.  Retrospective Design.	The study highlights how the decision to have reconstruction or not, is governed by many variables which are indirectly associated with age and ethnicity.

Author/ Year	Quality score (%)	Size	Title	Aims	Method	Clinical Relevance
Rubin & Tanenbaum, 2011  U.S.	75	13	"Does that make me a woman?": Breast cancer, mastectomy and breast reconstruction decision among sexual minority women.	How decisions about reconstruction are considered and how sexual identity affects these decisions.	Theoretically driven thematic analysis. Semi-structured interviews with n=11 women who underwent reconstruction and n=2 who did not.  Retrospective Design.	The article places breast reconstruction within a feminist context, and the need for health professionals to consider the views of women who do not identify themselves as being heterosexual.

## **Publication Bias**

Publication bias occurs when published studies are systematically different from non-published studies in favour of demonstrating positive findings (Dickersin, 1990). Comparisons between published and non-published qualitative research reveals a publication bias towards research that is higher in quality (Petticrew et al., 2007; Toews et al., 2016). 'Higher-quality' has been found as being determined by the clarity in which the methodology and findings are reported within the abstract (Petticrew et al., 2007). This can contribute to under-representing peoples' experiences of a given phenomenon (Lewin et al., 2015). This may impact on the present findings given that published and peer-reviewed studies have been selected for review. Limiting the search to studies written in English may have also limited women's experiences of having elective breast surgery from non-English speaking cultures.

## **Quality Appraisal**

Quality scores ranged between 50% and 95% (see Table 2). Higher scoring studies more adequately fulfilled the CASP criteria. Higher scoring studies also showed greater acknowledgement of the researcher's role whereas this was minimal to absent in lower scoring studies. For example, whether authors considered their own role in the development of the interview questions and data collection. All lower scoring studies scored partial points for ethical issues with higher scoring studies providing greater evidence of ethical practice. For example, it was unclear whether participants in some studies received clear information around the nature of the study and the risks of taking part. Lower scoring studies scored partial points for providing limited information around how data analysis was performed. For example, Neil, Amstrong & Burnett (1998) and Reaby (1998) reported either using 'qualitative methods' or 'qualitative enquiry' to analyse their interviews. Reaby's (1998) study was driven by an existing decision-making framework thus not reflecting the truly inductive approach of qualitative methodology. The highest scoring studies were those scoring between 90-95% (in descending order) Jerome-D'Emilia, Suplee, Boiler & D'Emilia (2015), Rubin et al. (2013) and Harcourt & Rumsey (2004). The lowest scoring study (50%) was a study by Lee, Hultman & Sepucha (2010). Little detail was provided in respect to participant characteristics, recruitment, data collection, analysis and ethical practice. It

was also not clear as to what findings were revealed from the focus groups and those from the 1:1 interviews, given that the outcomes of both were amalgamated. This was also true for women who had and who did not have a reconstruction; these findings were not separated based on the surgical choices made.

### **Description of Studies**

Twelve studies were included for review, of these studies, seven were from America, three from the United Kingdom, two from Australia and one from Canada. Eight studies explored women's decisions around breast reconstruction and four studies explored decisions for CPM. The ratio between studies exploring reconstruction versus CPM likely reflects trends for each surgical type over time; breast reconstruction has been more widely used since the 1970s compared to CPM which has drawn the attention of researchers within the last decade (Agawal et al., 2015; Angelos et al., 2015).

Rendle et al. (2015) interviewed nine women from an original subset of 41, to explore women's decisions to undergo CPM. Interviews were analysed using grounded theory methods. Each participant underwent four interviews, however, the recruitment method reflected that of the original study (see Beryl et al., 2016). The participants had a mean age of 48 years and had Ductal Carcinoma in Situ (DCIS) or stage 1 cancer. Decisions were made based on women's present and future anticipation of worry, as well as the inconvenience of continued surveillance on the contralateral breast. Participants' decisions were more closely aligned with the emotional rather than medical benefits of surgery. Similar findings were revealed by Beesley, Holcombe & Salmon (2013) who reviewed clinical case notes of 60 patients to explore the reasons for CPM in a single U.K. centre. The authors also interviewed four surgeons to clarify patients' case notes. Psychological reports revealed how most women made their decision based on their fear of cancer recurring and/or for symmetry reasons. Women were found to take an 'all or nothing' approach to managing their risk. In a study led by grounded theory, Covelli et al. (2015) explored 29 women's decisions to have a mastectomy for early stage breast cancer, including mastectomy of the affected breast and unaffected contralateral breast. 'Taking control of cancer' was a key theme within the

study, whereby decisions to have a CPM were influenced by women's fear of cancer and the desire for breast symmetry.

Similarly, Jerome-D'Emilia, Suplee, Boiler & D'Emilia (2015) explored reasons why 23 women chose to undergo a bilateral mastectomy irrespective of the stage in which cancer was diagnosed. All women underwent breast reconstruction. A thematic analysis revealed that women's decisions to have CPM were influenced by their fear of cancer recurring and a desire to avoid adjuvant therapy. Nine women were recommended by their surgeon to have CPM. A limitation of this study, however, is that the extent to which women were at risk of developing contralateral breast cancer was unclear, possibly reflecting the actual experiences of women in the study who received inconsistent reports about their risk from medical professionals. However, women with a known BRCA 1 & 2 mutation were excluded from this study.

Lee, Hultman & Sepucha (2010) explored patients' goals and concerns relating to 65 women's decisions to have or not have a breast reconstruction. Women were interviewed 1:1 or took part in a focus group; transcripts from these were analysed using a thematic approach. Reasons for reconstruction were associated with wanting to look natural in clothing and not wanting to wear a prosthesis. Women in this study hoped to have more information about recovery time and the impact of having further surgery. In a similar, but higher quality study, Harcourt and Rumsey (2004) interviewed 93 women who were recruited from multiple hospital locations; 37 had immediate breast reconstruction and 56 had opted against the procedure. More than half of the women (63) completed three interviews, one prior to surgery followed by 6 and 12 months later. Thematic analysis contributed to the development of a decision-making model whereby women were found to take one of three paths: instant immediate, information seeking, or indecisive decision-makers. These paths were determined by the speed of the decision, the information women sought, the emotion involved, and the decisiveness of the decision. Instant decisions were made primarily amongst women who did not elect to have a reconstruction.



Begum et al. (2011), used framework analysis to interpret the semi-structured interviews exploring 23 women's experiences of deciding to have immediate or delayed autologous reconstruction. Participants had a mean age of 48, had high educational levels and over half of the sample were married. Immediate reconstruction was described in respect to wanting to regain body image and femininity whilst delayed reconstruction was talked about in terms of the dissatisfaction with the external prosthesis.

Neill, Amstrong & Burnett (1998) interviewed 11 women from a single health centre at least twice, to explore the factors that led them to opt for a reconstruction. All but one participant had an immediate reconstruction. A thematic strategy contributed to the authors developing a decision-making process model. An overall theme of 'getting my life back' drove the decision-making process which involved: information seeking, talking it over and seeking normality. Getting one's life back also involved achieving normality, which included returning to work, avoiding a 'maimed' appearance and not having to explain one's physical self to others.

The following studies largely challenge the status quo of the previous articles described, paying attention to the decisions made by women belonging to an ethnic minority and women who identify themselves to be either lesbian or bisexual. Rubin et al. (2013) explored the decisions made by African American women using semi-structured interviews and grounded theory analysis. Participants had their mastectomy between one and eight years previously, with 23 out of 27 women having had a reconstruction. Findings revealed the influence of spirituality on the decisions of whether to reconstruct and on the type of methods used. Surgeons were found to use young age to influence women's decisions to have reconstruction. The authors describe the term 'stratified biomedicalisation' to describe the complexities of age, gender, ethnicity on influencing the decision to have reconstruction.

Boehmer, Linde & Freund (2007) explored decision-making for reconstruction amongst lesbian and bisexual women. Fifteen participants and 12 support people were interviewed to gather their perspectives on reconstruction. The authors interviewed partners to challenge the existing 'heterosexual

framework' in studies exploring reconstruction whereby the views of male partners (rather than female partners) are generally more considered. Eight women opted for reconstruction and seven women chose against the procedure. All women placed value in their overall well-being over their body image. Building on this study, Rubin & Tanebaum (2011) interviewed 13 lesbian and bisexual women, and performed a theoretically-led thematic analysis to reveal themes similar to studies exploring heterosexual experiences. The authors highlight how reconstruction may serve to protect others from the impact of cancer and to hide an image of illness. Decisions to have reconstruction were based on wanting to feel normal, to forget about cancer, to regain femininity and to avoid wearing a prosthesis.

In an older study by Reaby (1998), the decision-making styles of 64 women were explored based on a combined framework of Janis and Mann's conflict model and Simon's notion of bound rationality. Reaby developed a decision-making model based on women who had and had not undergone breast reconstruction. Women were encouraged or discouraged to have reconstruction based on their age. Decision making was divided between women who made quick decisions to those who spent more time deliberating and having more of a passive role in the process.

## **Synthesis**

A thematic synthesis was applied as described by Thomas & Harden (2008; see Appendix H). This method has been used specifically in health care to explore decision-making in cancer (for example, Morton, Tong, Howard & Snelling, 2010). Line-by-line coding was conducted in the results section of each study leading to the development of descriptive codes (Appendix I). Descriptive codes were listed (Appendix J) and clustered based on their similarities, which formed the analytical themes (Appendix K). Validity was increased through an iterative process of continuously checking themes and codes against the original data. The themes were scrutinised by a second reviewer.

### **Cancer and the vulnerable self**

The descriptions that comprise this theme mostly arose from studies exploring the decision to have a CPM, as studies exploring reconstruction did not focus on participants' experiences of being diagnosed with cancer.

Receiving a diagnosis of cancer had varying degrees of impact on the individual, with one woman describing feeling "unbalanced" (Neill, Armstrong & Burnett, 1998) by the diagnosis of a potentially terminal illness, with another feeling as though cancer had "rampaged" her body (Covelli et al., 2015). Other women described having a prolonged sense of disbelief towards their diagnosis (Jerome D'Emilia et al., 2015). The diagnosis for some women was accompanied by a great sense of vulnerability (Beesley et al., 2013) and fear of cancer recurring (Covelli et al., 2015). Reconstruction was described as a means of no longer being a victim to cancer (Rendle et al., 2015) suggesting a sense of vulnerability to the disease, which shaped their decisions to either have or not have elective surgery.

### **Life is on hold: seeking and assimilating information**

The notion of life being on 'hold' around the time of diagnosis was described. Some women directly referred to life being put on hold (Beesley et al., 2013), whilst others referred to not wanting to wait (Harcourt & Rumsey, 2004) and wanting to live (Covelli et al., 2015). This theme reflects a time in which women assess the risks, benefits, timing and method of surgery. This process was facilitated by seeking out information (including religious texts; Rubin et al., 2013) and/or talking with others (either their surgeon, family members, friends or support groups; Covelli et al., 2015; Harcourt & Rumsey 2004; Jerome D'Emilia et al., 2015; Lee, Hultman & Sepucha, 2010; Neill, Armstrong & Burnett, 1998; Reaby, 1998). The speed, extent and intensity in which information was assimilated, varied between the women. Some women described being selective and avoided negative information (Harcourt & Rumsey, 2004; Jerome D'Emilia et al., 2015; Rubin & Tanebaum, 2011; Reaby, 1998).

### **Trust versus mistrust**

For some women, once they had assimilated relevant information, their degree of trust in either, the medical professionals (Begum et al., 2011; Jerome D'Emilia et al., 2015; Rubin et al., 2013), surveillance methods (Rendle et al., 2015) or reconstruction techniques (Lee, Hultman & Sepucha, 2010), dictated their overall decision. Women who doubted the reliability of certain reconstruction methods, for example silicone implants, would either choose autologous methods or opt against reconstruction (Lee, Hultman & Sepucha, 2010; Rubin et al., 2013). Other women expressed fear that reconstruction could advance their cancer or trigger a recurrence (Harcourt & Rumsey, 2004).

### **Decision making and finding meaning**

After seeking out necessary information and speaking with others, women sought meaning to either clarify or validate their decision (Neill, Armstrong & Burnett, 1998). Finding meaning was informed by whether they placed trust in aspects of their treatment or surgery. For some women, meaning was ascribed to the decision based on societal views of wellness and female body image. For other women, the decision was a pragmatic one.

### ***Restoring wellness***

Restoring wellness included feeling physically and emotionally well, encapsulating many concepts such as: no longer looking like a sick person (Rendle et al., 2015; Rubin & Tanenbaum, 2011); covering up cancer (Begum et al., 2011); appearing well to others (Boehmer, Linde & Freund, 2007; Rubin & Tanenbaum, 2011) and; restoring body image, normality (Neill, Armstrong & Burnett, 1998) and symmetry, in order to reduce anxiety (Covelli et al., 2015). In contrast, restoring symmetry by means of reconstruction was also a cosmetic decision and not always explicitly related to restoring wellness (Rubin et al., 2013). Normality was a key theme amongst women electing reconstruction, which was also described as a means of restoring femininity (Begum et al., 2015).

### ***Pragmatism***

Some women described their reasons for the timing of surgery. Immediate reconstruction was elected based on the practicalities of having only one

operation (Begum et al., 2011; Harcourt & Rumsey, 2004) or not having to be placed on a waiting list (Harcourt & Rumsey, 2004), or due to not having a choice (Begum et al., 2011). Some women described wanting CPM to avoid having to return to hospital due to childcare (Rendle, et al., 2015). Conversely, women who underwent delayed reconstruction described the inconvenience of using a prosthesis (Boehmer, Linde & Freund, 2007; Lee, Hultman & Sepucha, 2010; Neill, Armstrong & Burnett, 1998; Rubin et al., 2013), with it being uncomfortable or not matching a woman's skin tone (Rubin et al., 2013). Women who opted to have CPM did so due to not wanting to continue with surveillance on the remaining breast. Whilst this was sometimes related to fear of a recurrence, this was a pragmatic decision for some (Jerome D'Emilia et al., 2015).

### **Preventing a vulnerable and uncertain future**

This theme reflects how decisions for elective surgery were made based upon preventing or avoiding adverse events in the future, including having a secondary breast cancer diagnosis (Beesley et al., 2015) or a vision of having no breast (Begum et al., 2011). For some women, this meant having a CPM to 'take control of cancer' (Covelli et al., 2015) or to reduce a low risk of future breast cancer recurrence, to one that is even lower (Rendle et al., 2015).

Women who deliberated over having a breast reconstruction were concerned about the impact of a reconstruction on future surveillance (Lee, Hultman & Sepucha, 2010; Rubin et al., 2013). This was determined by the degree in which they trusted the surgical or surveillance method. Others feared having future surgical complications or having to commit to life-long surgery if opting for an implant reconstruction (Rubin & Tanenbaum, 2011). The decision to have CPM was influenced by wanting to avoid future regret (Jerome D'Emilia, 2015; Rendle et al., 2015).

### **Moving on and reflecting back**

The theme of moving on is associated with life being on hold after receiving a diagnosis; women negotiate ways of moving forward with a life without cancer. Women reflected on their experiences, and breast reconstruction and CPM were ways in which 'moving on' could be achieved. This theme is evidenced

by statements such as to 'get life back' (Covelli et al, 2015) to put cancer 'behind' (Neill, Armstrong & Burnett, 1998), to move life along (Jerome D'Emilia et al., 2015) and to get on with life (Beesley et al., 2013; Neill, Armstrong & Burnett, 1998; Rendle et al., 2015). This finding is similar to Greener (2015) who described how women electing to have CPM want to get off the 'medical rollercoaster' after being diagnosed.

### **Minimisation**

Spontaneous statements such as: get 'rid of' [the contralateral breast] (Beesely et al., 2013), "... just take them both" (Rendle et al., 2015) "...get it done.." (Jerome D'Emilia et al., 2015) and "just do it" [have a reconstruction] (Begum et al., 2011) appeared to minimise the decision-making process. However, this may also be evidence of women disconnecting from their experiences as found by Greener (2015) in women electing CPM. These spontaneous statements appeared to provide a means of moving on from cancer.

The themes of the synthesis are illustrated in Figure 2, which maps the decision-making processes of women who are considering elective surgery.

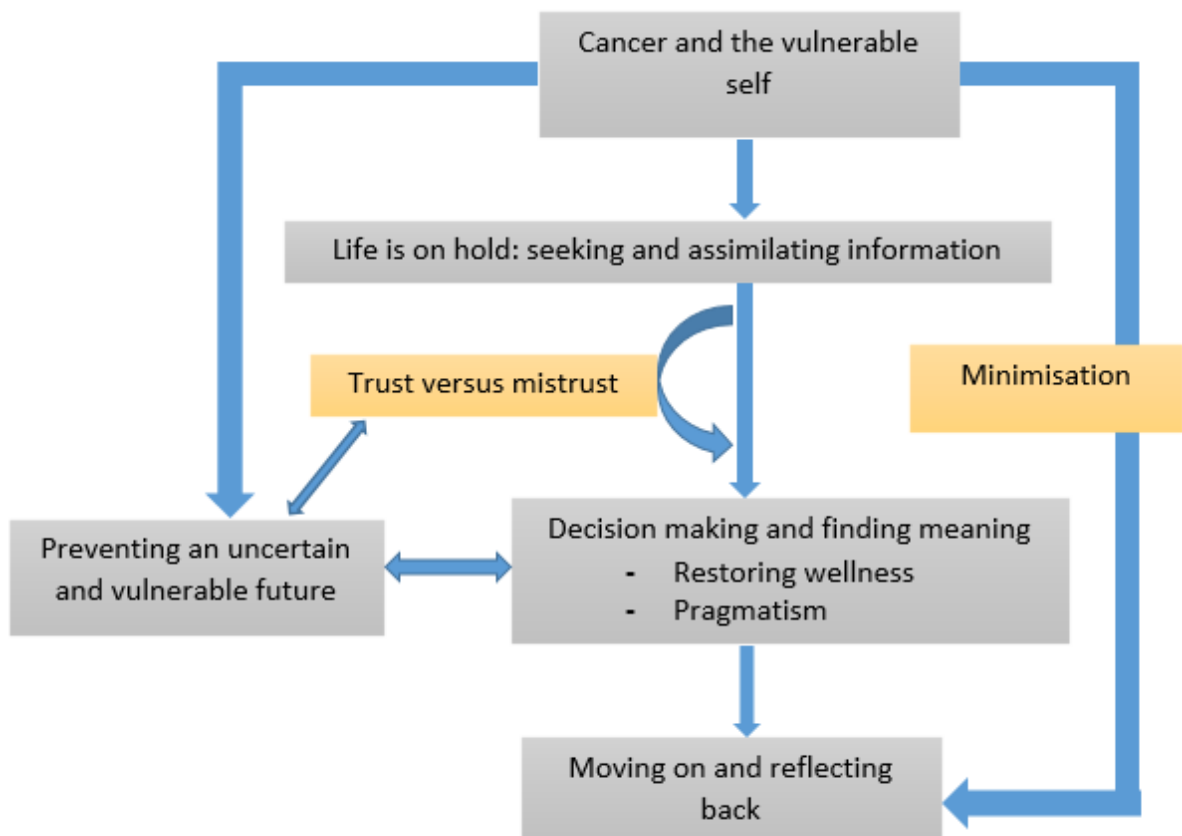


Figure 2.

*Decision-Making Processes for Elective Surgery*

## Discussion

The aims of this review were to identify processes that underlie women's decisions to have a breast reconstruction or a CPM. The decision-making process model illustrates non-discrete pathways that women take when deciding to undergo surgery. Women initially experience a sense of vulnerability after being diagnosed with breast cancer; they are presented with a potentially life threatening disease and are then required to make a plethora of decisions. Women go on to seek relevant information to meet their needs, or they ascertain relevant information during their initial appointment to make a decision. Decisions are guided in part by whether they trust the treatment and surgical options presented to them. Women make sense of their decision by finding meaning; this may involve restoring a sense of wellness or it may be a pragmatic decision, or one where predominantly the future consequences of their present decision are considered.

This model can be understood by various social, cognitive and emotional processes that are triggered in response to having a cancer diagnosis. Based on Leventhal's theory of self-regulation (1992), individuals are motivated to maintain homeostasis and return to normal following a threatening event. Women achieve normality through various means of coping, for instance, through actively seeking or avoiding information and then finding meaning in their decision (Ogden, 2007). 'Minimisation' could be viewed as an attempt to rationalise and exert control (Ogden, 2007) over an illness which could be perceived uncontrollable and incomprehensible. Women also assert mastery over their situation by way of attempting to prevent a cancer recurrence (theme name, 'preventing an uncertain and vulnerable future') which some women believe is within the boundaries of their control. Women's decisions to have elective surgery are also informed by their own beliefs and attitudes, (including those of others), towards the different surgical and surveillance methods, which help to predict their intended decisions (see Azjen, 1991). Following these processes, women's decisions to have elective surgery provide the means of returning to normal (for example, 'moving on and reflecting back'), thereby resuming homeostasis.

### **A contextual paradox**

Decisions for elective surgery are situated against a backdrop of paradoxes that exist between reconstruction as a cosmetic surgery and CPM as a treatment for the prevention of cancer. Yet, there are considerable similarities in the decision-making processes.

Firstly, women electing CPM are described as making a decision based on their emotional needs (Rendle et al., 2015) specifically, their fear of cancer recurring (Covelli et al., 2015). This leads women to develop a subjective, and over-estimated assessment of their risk (Beesley et al., 2013; Covelli et al., 2015). Paradoxically, reconstruction is cited as being an emotional response to losing a breast (Begum et al., 2011). There is also some evidence that women are subjectively encouraged or discouraged from having breast reconstruction based on their age, and in the absence of medical contraindications (see Begum et al., 2011; Reaby, 1998; Rubin & Tananbaum, 2011; Rubin et al., 2013). Although such reasons are often satisfactory to



some women, it poses a question as to whether these reasons are any more justified, or any less subjective than women wanting to have surgery based on a fear of cancer recurrence.

Secondly, there are many authors who describe how women electing CPM are not informed of their risks; there is evidence reported by Jerome D'Emilia et al. (2015) that some women avoid negative information when electing this surgery. Conversely, women's decisions to have reconstruction are often made without a full awareness of the risks involved (Boehmer, Linde & Freund, 2007; Lee et al., 2010; Reaby, 1998; Rubin & Tanebaum, 2011) with some women actively avoiding information that would deter them from their decision (Harcourt & Rumsey, 2004). Two U.K. studies have found that women do not always receive adequate information about their breast reconstruction, and feel ill-prepared for the after-effects of surgery (Potter, Mills, Cawthorn, Wilson & Blazeby, 2013; Wolf, 2004). New guidelines have since aimed to address this issue (Rainsbury & Willett, 2014). Despite this, unlike women who chose to undergo reconstruction in the absence of knowing the full implications of surgery, women who are electing to have CPM without considering the full risk to benefit ratio are cited as being "vulnerable" (Ashfaq et al., 2014; Basu et al., 2015).

Research exploring the information needs of women undergoing surgery suggest that the medical team can have a key influence on the woman's overall decision (Wolf, 2004). This poses many challenges to professionals given that conversations surrounding treatment options are likely informed by: personal and professional values of non-maleficence, societal norms of female body image, societal illness-perceptions of mastectomy, service provision norms and healthcare agendas. To deconstruct these influences in a time constrained health service is not easy. However, given the similarities in the decision-making processes, existing tools (e.g. Sherman et al., 2014) could be adapted to support women's decisions to have CPM and a breast reconstruction.

## **Limitations**

Studies exploring CPM did not always disclose whether women carried a genetic risk for contralateral breast cancer, and not all women underwent genetic testing. The findings should be taken with caution in that women may have been advised to have CPM based on their high risk; women's fear of cancer recurrence may have therefore been expected based on their objective degree of risk for contralateral breast cancer.

Qualitative synthesis involves a second order approach to interpretation; it is an interpretation of an interpretation (Ring et al., 2011). The results of the research are at risk of bias by the author's interpretation, with a greater focus towards psychological rather than medical or surgical risk of undergoing either surgery. Furthermore, higher quality studies contributed to the scaffolding of the model and it is thus influenced by the theoretical underpinnings of those studies. Also, Jerome D'Emilia et al. (2015) was the highest quality paper which may have placed a disproportionate influence on the themes. Conversely, this could have also ensured that the developing themes grew from studies with greater reliability and validity.

## **Clinical Implications**

Clinical Psychologists working in oncology can support women with their decisions by enabling them to explore the reasons for wanting (or not wanting) further breast surgery (for example, breast reconstruction or contralateral prophylactic mastectomy). This would include enabling the person to discuss their own experience of cancer, alongside their personal history and how this relates to their decision to have elective breast surgery. This would also provide women with the opportunity to discuss any anxiety surrounding issues of trust towards the medical team, fear of implant methods or the effectiveness of surveillance in detecting a future cancer. In doing so, a person can have a greater awareness of the reason for their decision, which alongside realistic surgical expectations could improve: shared decision-making, satisfaction with the decision and improve body image following surgery. Consequently, Clinical Psychologists should be available for *all* women who wish to consider the possibility of further elective breast surgery, irrespective of their surgical choice. Based on the findings of this review, contralateral prophylactic

mastectomy in absence of a risk reducing benefit, should be viewed no more controversial than women electing to have a breast reconstruction in absence of knowing their full surgical risks.

The experiences of women who chose not to have a reconstruction were explored in the studies under review. The descriptions that arose from women's accounts were often embedded within female body image ideals. Given that some women undergoing delayed reconstruction often do so due to the inconvenience of a prosthesis, it would be important to explore how some women overcome these inconveniences and choose not to reconstruct. This would have clinical value for women who are unable to have a reconstruction or who do not wish to pursue further surgery.

In addition, no study explored how women experienced their remaining breast following a mastectomy. Further research is required to determine how generally women feel towards their remaining breast and the meanings that are ascribed to the breast, specifically in relation to fear of cancer recurrence. This could help inform psychological interventions that could relieve women's fear of cancer returning, without having to undergo elective surgery.

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## Paper 2

### **“It’s All About Balance...”: Women’s Experiences of Having One Breast**



**Word count: 8160**

## **Journal Submission Details**

This paper has been written with the aim of being submitted to the Journal of Psychology and Health (see Appendix L), selected due to its focus on illness attitudes, behaviour and communication within healthcare. The following paper meets the journal requirements of having a maximum of 30 pages for submission, including references.

## Abstract

**Background.** Paper 1 revealed how elective breast surgery provided the means to move on from having cancer. Breast reconstruction restored femininity and body image, whereas contralateral prophylactic mastectomy removed the possibility of cancer recurring. Little is known about the experiences of women who do not have elective surgery and specifically how they experience their remaining breast.

**Objective.** To explore women's experience of having one breast following a mastectomy. Women's experiences of managing the physical imbalance caused by having one breast are also explored, including how they perceive their remaining breast.

**Design.** Semi-structured interviews were carried out with seven women 6-35 months post-mastectomy. Women were recruited from out-patient departments from two NHS Trusts. Women were aged between 46 and 77. Interviews were analysed using Interpretative Phenomenological Analysis.

**Main Outcome.** Three superordinate themes and 11 subordinate themes were identified. These centred around women receiving and managing the impact of the diagnosis and breast cancer surgery; the perceived sense of connectedness in which breasts were experienced to share and; the ways in which women moved forward with their lives with one breast.

**Results.** The meanings ascribed to breasts pre-mastectomy were lost following surgery, rendering the remaining breast as burdensome. Women identified themselves as having a coherent sense of self which helped them to manage the emotional and physical changes of breast cancer.

**Conclusion.** Women managed their changed bodies and social identities through using a breast prosthesis and through finding value in other aspects of their lives. Disconnecting from the meanings they ascribed to their breasts helped the women to cope with their loss, whilst also potentially preparing them for a cancer recurrence.

## Introduction

Little attention has been given to women's experience of their remaining breast following a mastectomy. Women's experience of having one breast is explored through their experiences of having a mastectomy and the impact that this has on their body image, identity, femininity and womanhood (Cromptvoets, 2006; Fallbjörk, Salander & Rasmussen, 2011; Koçan & Gürsoy, 2016; Manderson & Stirling, 2007; Piot-Ziegler, Sassi, Raffoul, & Delaloye, 2010). Women with one breast can also be identified in the literature through studies that explore women's decision-making around having a reconstruction. More recently, some authors (for example, Archer, Holland & Montague, 2016; Héquet et al., 2013) have focused solely on women who choose not to have a breast reconstruction; a novel research focus amongst a plethora of literature that combines women's decisions to have no reconstruction, with those who do. Furthermore, the experiences of women with one breast are often lost in quantitative research that compares breast conservation surgery outcomes, with mastectomy, immediate and delayed reconstruction. Specifically, with a focus on quality of life (Stavrou et al., 2009), body image, psychosocial functioning (Metcalf et al., 2015; Nicholson, Leinster & Sassoon, 2007) and satisfaction (Ng et al., 2014). Most commonly however, all current literature focuses on the absence of a breast or the absence of the reconstruction. Little attention is paid to what remains present, and yet there is an online interest amongst some women about what it is like to live with one breast: "how is life with one boob?" (breastcancer.org, 2017).

Breast asymmetry following mastectomy can be difficult for some women (Fallbjörk, Salander & Rasmussen, 2011; Reaby, 1997) who describe having "visual disharmony" (p. 493, Piot-Ziegler et al., 2010). This results from having to alter clothing styles (Cromptvoets, 2006) and having to manage the use of an external prosthesis, which as one woman described "at the end of the day....it probably would have been easier if you lost two" (p. 84, Hill & White, 2008).

### **Psychosocial outcomes: mastectomy versus breast reconstruction**

There is conflicting evidence supporting the psychosocial benefits of having a breast reconstruction over having a mastectomy alone, likely influenced by

flawed methodological research in this area (D'Souza, Darmanin & Fedorowicz, 2011; Harcourt & Rumsey, 2001). A recent U.K. audit (Jeevan et al., 2014) found breast reconstruction to have a positive impact on women's reported physical appearance and general well-being than those who opted for mastectomy without reconstruction. Other studies (outside of the U.K.) support findings consistent with the audit (for example, Fang, Shu & Chang, 2013; Ng et al., 2014).

Conversely, psychological distress has been found to improve over time irrespective of having a breast reconstruction (Harcourt et al., 2003). Also, reconstruction has not always been found to improve psychological outcomes or quality of life (Nicholson, Leinster & Sassoon, 2007; Raaff, Derks, Torensma, Honig & Vrouenraets, 2016), with some authors finding reconstruction to have a detrimental impact on psychological well-being (Metcalf et al., 2015). Some women perceive the reconstructed breast as being as part of the problem and not the solution, despite improvements in body image over time (Hill & White, 2008). The National Institute for Health and Care Excellence (2009) specify that breast reconstruction should be offered to all eligible women at the time of their mastectomy. Despite this, substantially more women do not undergo this procedure when compared with those who do, irrespective of the timing of reconstruction (Jeevan et al., 2014).

### **The contralateral breast**

Women's experience of their remaining breast following mastectomy has recently drawn the attention of researchers through the growing trend towards contralateral prophylactic mastectomy (CPM). This is a surgical procedure that involves the removal of the remaining, healthy breast. CPM is increasing in the U.S. at a rate which contradicts the actual incidence of contralateral breast cancer (Basu, Barr, Ross & Evans, 2015) and irrespective of risk (Beesley, Holcombe & Salmon, 2013). Women who are deemed to be at high risk of developing contralateral breast cancer, and who would benefit most from the procedure, account for a small percentage of this rise (Hawley et al., 2014). There is little evidence however, of the survival benefits in women who are not considered to be high risk (Angelos et al., 2015). Women are requesting to have their remaining breast removed due to their fear of cancer returning and

their desire for breast symmetry (Buchanan et al., 2016; Covelli, Baxter, Fitch, McCready & Wright, 2015; Jerome-D'Emilia, Suplee, Boiler & D'Emilia, 2015).

### **Deciding against reconstruction**

Women who elect not to have a reconstruction tend to be older in age (Fallbjörk, Karlsson, Salander & Rasmussen, 2010; Hamnett & Subramanian, 2016; Hequet et al., 2013), though they are also less likely to receive information relating to their reconstruction options when compared with younger women (Fenlon et al., 2013; Morrow, Scott, Menck, Mustoe & Winchester, 2001). Holland, Archer & Montague (2016) found younger women to experience the promotion of reconstruction as being a 'normal course' of treatment; the participants in this study described the difficulties they experienced when electing against the procedure within a pro-reconstruction surgical team. Rubin & Tanenbaum (2011) describe similar findings, whereby 'opting-out' of having a reconstruction was perceived to be a harder decision than to conform to the norm of reconstruction.

### **The present study**

Women elect to have a reconstruction or CPM to: achieve symmetry, restore wellness, reduce a cancer recurrence and remove the impracticalities caused by wearing the prosthesis. More research is required to explore how women overcome the imbalance of having one breast, within a pro-reconstruction health system. This includes how women manage their use of an external breast prosthesis. Such a finding is clinically relevant for women who do not wish to undergo further surgery or for women who are not eligible for reconstruction.

Further research is also required to explore the experiences of women with one breast who are not deemed to be at high risk of developing a contralateral breast cancer. Little to no research to date has explored how women generally feel towards their remaining breast following a mastectomy. This may give some insight as to why women may be electing to have a CPM and how women can manage their fear of cancer in the absence of undergoing further breast surgery. This information could be used to develop psychological



interventions that could help women overcome or manage their fear of cancer returning.

A critical appraisal of qualitative literature exploring the decision to have elective breast surgery (see Paper 1), revealed the need for future research to explicitly state the method of qualitative analysis and the researcher's own position towards the interpretation of data.

### ***Interpretative Phenomenological Analysis***

Interpretative Phenomenological Analysis (IPA) is a qualitative research approach developed by Smith (1996) that is committed to 'giving voice' (p. 101, Larkin & Thompson, 2012) to people's experiences of significant phenomena about which little is known (Smith, Flowers & Larkin, 2009). This research method is therefore appropriate to explore women's experiences of having one breast following a mastectomy.

Three core concepts theoretically underpin the application of IPA. These include: phenomenology, idiography and hermeneutics (Smith, Flowers & Larkin, 2009). Phenomenology is concerned with how individuals engage with and experience their social world, as they are immersed within it (Larkin & Thompson, 2012). The exploration of these experiences adopts an idiographic focus that requires detailed and in-depth understandings of the meanings a person ascribes to a given experience (Smith, Flowers & Larkin, 2009). Hermeneutics introduces an interpretative element to IPA in which a person's experience can only be accessed through their interpretation of events (Larkin & Thompson, 2012). This access however, is influenced by the researcher's own interpretation, referred to as a 'double hermeneutic' approach to analysis (Smith, Flowers & Larkin, 2009)

### ***Reflexive position***

The researcher is a Trainee Clinical Psychologist who is interested in women's health and body image, garnered through her experiences of working within oncology and physical health settings. A feminist perspective is adopted alongside a psychological approach to deconstruct breast cancer research within a society that highly regards female beauty and feminine

body-image ideals. For this reason, the researcher also attends to how breast loss and reconstruction is socially constructed.

### **Aims:**

1. To explore women's experiences of having one breast following a mastectomy without reconstruction.
2. To explore women's experiences of their remaining, unaffected breast (specifically in women who are not considered to be at high-risk of developing a contralateral breast cancer).
3. To explore women's experience of managing the physical imbalance of having one breast.

## **Method**

### **Ethical considerations**

The study received Independent Peer Review approval (Appendix M) and NHS ethical approval (Appendix N) including site approval through three NHS Research and Development departments (see Appendix O, O2 & O3). Although three sites received approval, no participants were recruited from site 3 which was based in East Staffordshire. Informed written consent was gained at the start of each interview (Appendix P) whereby confidentiality and anonymity were explained. All participants were provided with the contact details of the supervising Clinical Psychologist if they felt in anyway distressed following the interview.

### **Participants**

#### ***Sample***

IPA employs purposive sampling to recruit individuals who can provide access into the experiences of shared phenomena (Smith, Flowers & Larkin, 2009). For the purposes of this study, the phenomenon of interest was restricted to women who had a unilateral mastectomy without electing reconstruction and who were not deemed high risk for developing contralateral breast cancer. IPA is suited to small sample sizes to gain detailed, in-depth accounts of peoples' experiences (Smith, Flowers & Larkin, 2009). For this reason, seven women

were recruited through two oncology outpatient departments affiliated with two NHS Trusts based in the Midlands (site 1) and in the South West (site 2).

### ***Inclusion and Exclusion Criteria***

Participants were included in this study based on meeting the following criteria:

- Over the age of 18
- Have undergone unilateral mastectomy for the treatment of breast cancer
- Were eligible for reconstructive surgery but had decided against this procedure
- Were able to give informed consent
- Were English speaking
- Were assessed as not being high risk for developing contralateral breast cancer

Women were excluded if the following criteria were met:

- Had a current diagnosis of breast cancer
- Were having further investigations in the contralateral breast
- Unable to have a reconstruction due to medical contraindications
- Were delaying reconstructive surgery due to receiving radiotherapy or chemotherapy
- Already involved in breast cancer research

### **Recruitment**

Recruitment packs were provided at each recruiting site. The researcher visited each site to discuss the research and to explain the recruitment strategy. The lead breast nurse at each site identified eligible women using the inclusion and exclusion criteria. Each site provided ongoing routine appointments for women up to five years following their diagnosis and hence, women within five years of their diagnosis were recruited to the study. The lead breast nurse posted or distributed 30 opt-in letters (Appendix Q) and participant information sheets (10 at site 1 and 17 at site 2; 3 at site 3; see Appendix R) to eligible women during routine clinic appointments. Women were given the opportunity to post their opt-in letter stating whether they wished to take part. Opt-in letters were returned directly to the researcher who

was then able to contact those who were interested and provide further information if required. Fourteen women responded and five declined to take part. In addition, one woman was not eligible and another did not leave her contact details (both from site 2). Reasons for not wanting to take part included: a recent bereavement (n=1; site 3); undergoing further investigation (n=1; site 3) and a long time since mastectomy (n=1; site 2). Two women did not provide reasons (site 2). Seven women agreed to take part. An interview time and date was agreed with all but one interview taking place in the participant's home. One interview was carried out in an interview room on the participating Trust's site. Two participants were recruited from Site 1 and the remaining 5 were recruited from Site 2; recruitment was carried out between September 2016 and January 2017. Descriptive information for all participants is reported in Table 1. All women were allocated a pseudonym for confidentiality.

**Table 1.** Demographic Information

<b>Name</b>	<b>Age</b>	<b>Marital status</b>	<b>Employment status</b>	<b>Education</b>	<b>Cancer stage</b>	<b>Time since mastectomy (Months)</b>
<b>Petra</b>	61	Married	Part-time	Degree	3	12
<b>Sandra</b>	58	Married	Unemployed	College	4	7
<b>Phyllis</b>	75	Widowed	Retired	College	3	18
<b>Maureen</b>	77	Widowed	Part-time Volunteer	High school	1	13
<b>Claire</b>	46	Married	Full-time	High school	0	6
<b>Sue</b>	70	Married	Part-time	Degree	2	36
<b>Louise</b>	68	Married	Retired	High school	0	35

## **Procedure**

### ***Participant Interviews***

Participants took part in a semi-structured interview. Interviews were recorded on a password protected dictaphone. Six interviews were conducted 1:1. One interview which was carried out with the participant's grown-up daughter in the room. Demographic information was collected before commencing the interview (see Appendix S). An interview schedule (Appendix T) was used as a flexible guide to ensure the researcher responded to the idiographic nature of interview. Audio files were transcribed verbatim by the lead researcher which, once completed, were replayed again to check for accuracy. All transcripts were anonymised. Transcription and reflective field notes were taken immediately following the interview.

### ***Data analysis***

IPA is a flexible approach which requires an attempt to develop an “organised, detailed, plausible and transparent” account of the data (p. 104; Larkin & Thompson, 2012). The method described by Larkin & Thompson (2012) was used to guide the analysis. NIVO Version 11 (2010) aided the organisation of the data. The analysis was conducted in the following stages:

*Stage one.* The first stage of the analysis involved free-reading and re-reading the transcript to allow the researcher to immerse in the data (Appendix U). Line-by-line analysis was then conducted (Appendix V) to develop detailed descriptions and/or meanings in the data that would lead to the emergence of preliminary themes. Descriptions were informed by conceptual and linguistic features of the text.

*Stage two.* Connections between the themes were identified and clustered into subordinate themes. An iterative process occurred whereby connections were checked against the original data. Clusters were formed based on the central concepts of the analysis, which would lead to the development of superordinate themes. This was repeated for each interview (Appendix W).

*Stage three.* Superordinate and subthemes were pooled together across transcripts and were viewed independently of one another (subthemes were not viewed as being connected to a superordinate theme). Connections across these themes were formed thereby building a preliminary structure (Appendix X). Consistent with high-quality IPA reporting as defined by Smith (2011), the final superordinate and subordinate themes were selected based on: their prevalence across the data, how well they represented the sample and how well they captured the overall variation of participants' experiences. Further supporting evidence of these themes is provided in Appendix Y.

## **Results**

All women had undergone their mastectomy within the last three years at the time of the interview (range = 6-36 months; mean = 18 months). All women

except for Maureen, had children. All women made their decision not to have reconstruction at the time of being diagnosed with cancer. Two women (Maureen and Louise) had a previous diagnosis of breast cancer in the same breast. All but one woman had completed treatment; however, not having completed treatment did not influence her decision not to have reconstruction. All interviews lasted between 38 minutes to an hour (mean time = 47 minutes).

Interpretative Phenomenological Analysis revealed the following superordinate and subordinate themes which are summarised in Table 2.

**Table 2.** Summary of Themes

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Coping across a cancer continuum	Damage Limitation “It Could be Worse” Mastering Mastectomy
A Breast Connection	A Changed Connection A Burdensome Breast An Inferior Replica Swiss Army Breast Breast Watchers
Finding Value Between Conflicting Identities	A Prosthetic Disguise Coherent Identity Valued Living

### **Coping across a cancer continuum**

Women described the impact of their cancer diagnosis, which varied along a continuum from person to person. The women attempted to take control over treatment decisions as well as the appraisals that helped them to accept their circumstances. Louise described feeling “devastated” (Line 46) by her news and Maureen described her sense of horror, believing “that’s the end” (Line 529). On the contrary, Phyllis and Petra did not experience shock towards their diagnosis: “it’s just another thing” (Petra, Line 54) and “I wasn’t shocked when they said you’ve got cancer” (Phyllis, Line 159). Their responses appeared to

be influenced by having various other health diagnoses in the past, which for some, prepared them for the effects of the illness.

### ***Damage limitation***

For five women, receiving a diagnosis of breast cancer triggered a threat response; the women were observed to either fight or fly to protect themselves from emotional harm. Some women's sense of fight was observed in their definitive decision to have a mastectomy before knowing any of their treatment options, often even before they were informed they had cancer:

"I knew it was, I already knew it was malignant. I knew before he told me....And I had already decided, erm, that I would have a mastectomy" (Petra, Lines 60-62)

"I'm going to just have it cut off, you can have it cut off I said *I'm going to have it cut off* and that was before I knew the options" (Sue, Lines 92-93)

Maureen and Louise avoided reading information about the procedure in attempt to reduce their worry. As described by Louise, blocking out details of her procedure and diagnosis helped her to remain calm: "...come the day when I... went in for the operation, I was just calm and that was it" (Lines 68-69). Petra's fight response also enabled her to 'hold' herself together until crying in relief once the operation was over. Their initial responses to their diagnosis therefore enabled them to cope and for some, reduced the overall emotional impact of their operation.

### ***'It could be worse'***

The participants attempted to make sense of their situation often using downward comparisons, or by comparing significant past life events to establish a sense of 'it could be worse'. This appeared to facilitate a process of acceptance. Louise rationalised that losing a leg would be worse, whereas Sue recognised "there isn't anything I can't do now that I used to do before" (Line 223). Such downward comparisons also helped Phyllis to accept her mastectomy scar: "it's not a bad scar um, I, I thought it would have been worse..." (Line 129).



Other women described how the mastectomy had not made a significant physical difference to their lives, specifically in regards to their choice to not wear low-cut tops. This indirectly suggested that their breasts are not a big part of how they look. Having breasts that were not a defining feature was often celebrated against other women whose breasts are part of their identity:

“I know certain of my friends that do, yknow, they always wear quite low tops, low cut tops and stuff, I think, I am not quite sure how they would cope with it, quite so well because that’s a big part of how they are...is how they look” (Claire, Lines 495-496)

The women therefore found individual merits in their situation and recognised their own personal strengths. The participants’ process of acceptance may have also been influenced by the positive role placed upon the breast nurses and female surgeons. Health professionals were commonly referred to being “they” whereas breast nurses were gendered (‘her’ or ‘she’) and were valued. For Claire, her female surgeon appeared to play a significant role in her overall experience and likened her to a ‘good seamstress’ given that she repeatedly described her as being “very good” (Line 29) and having “sewed me up very well” (Line 439).

### ***Mastering mastectomy***

Four women received their diagnosis with shock which led to catastrophic thinking and an increased sense of vulnerability. Other women found ways to assert control to get ahead of cancer, even when such opportunities for control were limited. For example, some participants reported that they would have elected a mastectomy anyway, despite not having a choice:

“...I just said yeah no, the whole thing off anyway... ‘cause I wouldn’t have wanted just a bit” (Claire, Line 51)

“It was just a thing in my head that said *get rid of it all*” (Phyllis, Line 16)

Phyllis also illustrated the idea that she is offering her body parts, as opposed to having them forcibly removed: “I am not dying, I’m givin’ myself away a bit at a time” (Line 940).

The decision of whether to have a reconstruction was one in which these women were solely autonomous, representing a clear avenue of control. For two of the women, this decision was made against the surgeon's promotion of the surgery:

"The surgeon asked me two or three times *are you sure you don't want reconstruction?* so he was quite a proponent of it" (Sandra, Lines 52-53)

"I had my annual check-up two weeks ago, and, I was offered it again, I won't ever say yes!" (Sue, Lines 225-226)

Maureen's decision not to have a reconstruction was partly based on her assumption that she should not have it due to her age. However, she said that she did not wish to undergo the procedure due to the extensive surgery time.

### **A Breast Connection**

This superordinate theme depicts the relationship that women share with their breasts, and how this can change after having a mastectomy. It is through this changed relationship that women's decision not to have a reconstruction can be better understood, and why their feelings towards their remaining breast alter. This theme also encapsulates the connections that women make with others through having had a mastectomy.

There was evidence from the interviews that some women viewed their two breasts in the context of the other. Claire described how checking her remaining breast has become more of a concern since her mastectomy as she has nothing to compare it against:

"I did sorta think ooo 'cause it was only very slight the bumpiness in that one, and I think "oh God" will I notice it if it's in that one? 'Cause it won't be vastly different 'cause I haven't got anything to check it against..." (Claire, Lines 277-278)

This sense of connectedness appeared to be held by Maureen's surgeon, who reassured her "that the other breast can start sort of coming out in sympathy..." (Line 48) in respect to the pain she was feeling in her remaining breast.

### ***A changed connection***

This theme refers specifically to women's changed connection with their breasts following mastectomy. Three women describe the relationship that they had with their breasts. Sandra's experience of cancer turns her remaining breast from a once valued friend into an appendage; the remaining breast has essentially been tainted with the same fate, as if it is now as disposable as the affected one:

"I was very affectionate towards them, they were my friends, but then of course yknow you get breast cancer and you realise actually that they are appendages on your body that you don't always need -and ifthey're going to become diseased then they need to be taken away" (Sandra, Lines 146-149)

Similarly, Louise described having always been "proud" (Line 90) of her breasts but after her mastectomy, gave little thought to her remaining breast: "I don't really think about that [the remaining breast]" (Line 286). Her connection to her contralateral breast contrasted with how she experienced her affected breast prior to her mastectomy:

"What was strange...when I knew I was having the mastectomy, and I treated the breast like a sick child, I found myself sitting here some nights, lying back just holding it..." (Louise, Lines 286-288)

Four of five married women described few changes within their intimate relationships following their mastectomy, or at least ascribed a lack of sexual intimacy to normal circumstances (prioritising children and work for example). Sandra's description of checking her remaining breast gave a stark contrast to any sense of sexual connection with her breast when she described having to give herself "a good old grope" (Line 574) when checking her other breast. Furthermore, Claire and Sue described showing their sons their mastectomy. Claire described how her boys wanted to see more "gore" (Line 398), whereas Sue said that her son had affectionately referred to her as "monoboob" (Line 175). Phyllis stated humorously "I can now do Mr and Mrs!" (Line 122) as if also inferring gender differences between her mastectomy and remaining breast. These descriptions appear to further remove the breast from a sense of sexual focus.

### ***A burdensome breast***

The subtheme relates to the physical and emotional hindrances that were described by the participants towards their remaining breast. Four women talked about having the contralateral breast removed, although sometimes said in humour, losing one appears equal to a cognitive and emotional loss of two. For example, Sue talked about using her prosthesis where she said “shame I didn’t say *why don’t you take both off* and then I needn’t bother with anything” (Line 172). Phyllis responded regarding her remaining breast: “So [to] be quite frank with you, this one gets in the way now!” (Line 45). Though Petra and Sandra described how they didn’t think about or look at their remaining breast as if they had split-off from any emotional connection.

For three of the women, the remaining breast became a ‘breast to check’, presenting them with a source of worry in regards to a cancer recurrence. Women who feared the return of cancer appeared to appreciate reassurance from their surgeon. This reassurance was also likely satisfied by the fact that the mammogram reliably detected their initial cancer. For Claire, her worry towards her remaining breast reflected the idea of having a ‘sinister twin’: a matching pair whose “sinister” (Line 365) difference was only detected by mammogram: “I suppose you just think if it was in that one why isn’t it gonna necessarily be in that one...” (Line 293).

### ***An inferior replica***

All participants decided against having a reconstruction around the time of their initial appointment with the surgeon. The women appeared to make a quick decision with little knowledge of the surgery. Although not initially explicit, their decision was compliant with their own personal values. Whilst Petra described researching the different methods, women mostly based their decision on the fact that it wouldn’t look like a real breast or match the remaining breast, and nor would it be responsive to weight changes (if having an implant reconstruction):

“Well it’s not gonna be like a real boob is it? So you might as well have nothing... it might look odd...odd-er...” (Claire, Line 258)

“I was worried whether one would look different to the other” (Louise, Line 111)

Sue described being against the decision because it “...smacks of... not plastic surgery, erm... yknow like having a nose job? Something that’s done...to make you look better and I’ve never, ever considered anything like that...” (Lines 266-272). Similarly, Maureen and Phyllis felt that it was a younger woman’s choice due to breasts being part of their physical sense of attractiveness. Hearing about other women’s difficulties after having a reconstruction, and the possibility of other surgery and ongoing pain also contributed to their decisions. Reconstruction would have also had an impact on the women being able to return to ‘normal’ sooner. Essentially a reconstructed breast would mean having to endure extensive surgery for the breast not to look the same or be responsive to bodily changes; an inferior replica for a high price.

### ***Swiss army breast***

This subtheme ‘swiss army breast’ developed from the versatile nature of the prosthetic breast, including its ability to ensure the women’s social survival. Participants described being able to swap the prosthesis for different uses (for example, swimming and yoga) as well as it being available in different sizes and textures (including a ‘softie’ or silicone). Phyllis went so far as making her own prosthesis for swimming, which she then used as a sponge to wash herself with afterwards. Whilst the prosthesis has clear physical uses, namely to restore a ‘normal’ female form, they also appeared to serve different emotional functions. For example, to protect oneself from appearing ‘odd’ or ‘abnormal’ to others, a seeming consequence of looking lopsided. Sue described her prosthesis as her friend; it isn’t part of her but is always with her. Claire however, was less concerned with her prosthesis, feeling comfortable not to wear it when doing her usual activities. Phyllis and Louise were keen to show their prostheses to the researcher. In this way, the prosthesis served as an educational tool to connect with the researcher on a personal level, in the same way women connect with others through their breasts following breast cancer.

### ***Breast watchers***

'Breast watchers' relates to the connections that women make with other women who have experienced breast cancer. This appeared somewhat akin to membership of a diet club; the general dissatisfaction towards their weight and being members of popular diet clubs were described by all participants, influencing the name of this theme. After having breast cancer, women are granted access to a community that is inclusive to women, and which provides opportunities to share knowledge and products that cater for women with one breast. Louise and Claire embraced the support received through this network and then identified their own positive influence on promoting breast cancer awareness:

"It's quite good for it to be out there for people to check and stuff, I think there are a lot of people that do promote it...and obviously after *me* having something done, it made all my friends check... and I just said, *if you feel any different just go to the doctors and get it checked out*" (Claire, Lines 332-339).

Despite the support, which Sandra describes as being "phenomenal", there is often a lack of emotional connectedness through such contact. For Sandra, communication occurs online, where she describes talking with others who are going through the "process" (Line 326) which she says helps to open avenues of "dialogue" (Line 334), descriptions which lack personal connectedness. Furthermore, the women described using humour between each other to avoid getting "too serious" (Louise, 172) and dwelling on their situation. Whilst this was observed to be a source of resilience for the women, humour appeared to hinder the development of authentic connections with others.

Through these avenues of dialogue, women were made aware of how common breast cancer is, which for some, seemed to result in a detachment from their own experiences, as if unable to acknowledge their own distress. Petra described her distain in regards to the connections she made through having to sit in the radiotherapy waiting room. She likened it to being part of an "exclusive club" (Line 471) that she did not wish to be a part of.

Conversely, great value was placed on other women who had experienced cancer and often word-of-mouth was found to have a strong influence on the decisions women made, specifically in respect to deciding against breast

reconstruction. The roles women took on to promote cancer awareness served to turn their negative experience into a positive one. In effect, the women reconstructed the meaning ascribed to breast loss in absence of a physical breast reconstruction.

### **Finding value between conflicting identities**

Participants were generally satisfied with their decision not to have a breast reconstruction, with most embracing the use of a prosthetic breast. Maureen, Louise and Sue opted to wear their prosthesis at all times; however, Petra, Claire, Sandra and Phyllis spoke about wearing it primarily when going out. This seemed to serve to 'look normal' to others, which in turn would deter any unwanted sympathy. In contrast, participants described being the same person and placing greater value, or refocusing value towards more important aspects of their lives. It appeared that the women were having to manage a conflict between their altered social identity and body image whilst holding on to coherent sense of self-concept.

### ***A prosthetic disguise***

Some women described wearing their prosthesis to look normal in public despite being satisfied with not wearing it at home. This appeared to result from a fear of being judged by others, arising from the belief that their cleavage was once, and continues to be a focal point of critique. Claire described wearing it when getting "dressed up" (Line 461), whereas Louise said she would look "peculiar" (Line 523) without it. Other women inferred that their breast loss would enable others the access into seeing their illness, a defect that could otherwise lead to them being treated differently. Sandra said she wears it because:

"I wouldn't want to draw attention to myself,... I suppose it's the *overall* "well you've got cancer, you need my sympathy" and I don't really want that, I want people to treat me as is, like I would anybody..." (Sandra, Lines 205-208)

Similarly, Sue described the importance of looking normal "outwardly" (Line 245) and compared losing a breast to having a disability, which would result in her being treated differently by others. Maureen stated:

“I think I’d be... quite embarrassed if, if anyone did see that I hadn’t got a breast... I don’t feel like a whole person anymore, a whole woman anymore” (Maureen, Lines 139-43)

The prosthesis serves to protect the women and others in their social world where it is assumed that illness and disability are negatively perceived. In addition, the prosthesis was found to protect the women from their own personal loss and altered body image.

### ***Coherent Identity***

Despite their acknowledgment of their physical change, the women described having a continual sense of self, as noted often by using “I am” statements throughout the transcripts. Phyllis was determined to state that she was still a woman: “I’m a woman I am, whether I have a breast or not, it makes no difference, I am *still* a woman!” (Line 43). Her strong sense of self was accompanied by a coherence towards her physical being; for example, despite having lost her breast, she described herself as still having “boobies” (Line 132) and washing under both breasts in the shower. Maureen described herself as being spiritually and emotionally the same person.

Whilst taking time to describe who they were, three women also described themselves as being ‘non-conformists’. Sue did not take the advice from her doctors following her surgery “I’m not very good at following advice, I tend to do what I want to do and think well, yknow, it’s my life” (Lines 147-148). Petra described being ‘different’ to other people: “I’m quite comfortable as I am I don’t feel I have to conform, I am who I am and I’ll do what I want basically” (Lines 560-561).

### ***Valued living***

This subtheme reflects on the women’s continual ability to live a valued life despite managing a physical change and altered social identity. Their ability to do so was facilitated by having clear valued paths for living, achieved through having personal philosophies or being guided by their faith. Sandra reflected on how having cancer brought her closer to her family. Petra also placed value on her family life and described herself as being a strong and positive person,



a mantra that has kept her moving forward in life in the face of adversity, for example, when she was diagnosed with a neurological condition:

“But you know my life didn’t change, I still played netball three times a week and I still had dinner parties and yes sometimes it wasn’t easy and I still have problems sometimes, erm but it’s all about balance isn’t it?” (Petra, Line 279-281)

Spirituality is an important part of both Maureen and Phyllis’s lives as illustrated by Phyllis:

“It is important to believe in something and God to me is somebody who is real erm, he isn’t just a little.... when I did my driving exam, I had him as my passenger and things like that, yknow? He’s a, he’s a person in my life...he’s a big influence, he’s my boss...” (Lines 64-66)

Maureen described what could be interpreted as ‘post-traumatic growth’ (Calhoun & Tedeschi, 2014), which followed from the death of her abusive husband; she has gone on to travel the world and in spite of having breast cancer twice (and her continuous fear of recurrence to the remaining breast), she resumed some normality in her life. She achieves this by recognising her sense of survival and her new found ability to have greater empathy for others.

Claire focused on getting back to aspects of her life that she most valued including exercising and keeping fit. Louise described wanting to look how she normally looks and for her, this involved integrating her prosthesis into her regular activities such as swimming and yoga, as well as maintaining her interest in fashion. All women described how their relationships with close friends and relatives remained the same following a mastectomy, and how they felt no different about themselves within these close circles. Despite the differences in the impact that cancer had, all women achieved a sense of normality whilst living with one breast.

## **Discussion**

This study explored women’s experiences of having one breast, including how the remaining breast is perceived and how the physical imbalance of the

breast is managed. Three superordinate themes were revealed from the interviews which centred around: receiving and managing the impact of the diagnosis and having a mastectomy; the perceived sense of connectedness in which breasts were experienced to share and; the ways in which women could move forward with their lives, alongside a life-changing surgery.

Women's different experiences of cancer and having a mastectomy (as described in the theme 'coping across a cancer continuum') were important to explore in relation to their decision to live with one breast. For most people, cancer presents itself as a crisis in a person's life (Owen, 2011) to which the women adapt in various ways. It is long documented (Taylor, 1983) that adaptation can occur by several cognitive processes such as: making meaning from the situation, developing a sense of mastery (depicted by the theme 'mastering mastectomy') and through self-enhancement (as described by 'it could be worse' and through meeting others through 'breast watchers'). These processes help to repair a sense of normality and self-esteem that is inevitably threatened by cancer (Taylor, 1983).

### **A 'workable' normality**

Women achieved a state of normality despite the challenges they faced with having one breast, particularly in relation to their altered social selves. The presence of their remaining breast and absence of the other, provoked feelings of sadness, shame, guilt and a fear that cancer will return. Indeed, it is not the absence of such feelings that contributed to their sense of normality, but their ability to accept these difficulties and commit to choices they care most about; choices that prove to be 'workable' in managing their distress.

'Workability' is the process in which a person's current means of coping leads them to live a fulfilling and meaningful life (Harris, 2009). This is the foundation of the therapeutic model Acceptance and Commitment Therapy (ACT). ACT is based on accepting difficult thoughts and feelings whilst being able to make choices (and act on those choices) that are consistent with what a person values (Harris, 2009). The model describes six concepts that can facilitate this process. The most relevant to the findings of this study are: 'Defusion', Acceptance, Values and Committed Action. Defusion involves separating

oneself from distressing thoughts and feelings, and to instead, 'make room' for these emotions through acceptance (Harris, 2009). By doing so, this can enable a person to live towards a life they value. A person's ability to do so and act within these valued directions defines the term 'committed action'.

Women achieved defusion through their ability to separate themselves from their negative thoughts and emotions, including the fear of a cancer recurrence associated with their remaining breast. This was facilitated by their ability to normalise their emotions and by having insight into their thoughts (Harris, 2009). For example, Claire acknowledged her fear of cancer recurrence and rationalised her thought about the likelihood that it would recur. Other women normalised their emotions through the support of others, whilst also being reassured by the breast care team.

Through the process of defusion, women could focus on what they valued (for example, family life, sport, fashion) and take committed action. For example, choosing to wear a prosthesis instead of having a breast reconstruction. This was likely facilitated by the women having a strong sense of who they are, as described by the theme 'coherent identity', and due to the consistency of their personal relationships. Aiding this process was their ability to accept their circumstances, which for some, was influenced by their experiences of past traumatic events; women thus had access to previous social experiences that informed their ability to cope (Brennan, 2007).

### **A societal imbalance**

On the contrary, the need to always wear the prosthesis (especially in public) was unlikely to be a valued-based decision. The prosthesis served to disguise the women's changed bodies (described by the theme 'prosthetic disguise'), which some experienced as being defective following their mastectomy. The prosthesis helped women to avoid these thoughts and feelings towards their bodies. It also protected some women against societal views of illness whilst maintaining the social meaning attached to their breasts as being a focus of femininity and attractiveness (Salter, 1997). In ACT, avoidance or suppression of negative thoughts and emotions is referred to as being 'experiential avoidance' (Harris, 2009). Avoiding, rather than accepting or acknowledging

these difficulties may increase the women's distress overtime (Hayes, Luoma, Bond, Masuda & Lillis, 2006). However, overall, the prosthesis served to manage both a physical, cognitive and emotional imbalance that resulted from having one breast.

### ***Battle of the breast***

Women's relationship with their remaining breast can also be understood in the context of a breast cancer society. Breast cancer campaigns over-expose women to the risks of the illness (Orenstein, 2013) whilst highlighting the extent of its prevalence. The prevailing message is one where women are encouraged to 'fight' and 'beat' cancer (Parkinson, 2003). In doing so, women are themselves placed under attack to remove the disease (Kasper, 1995). Consequently, women try to "get ahead" of cancer (Rendle, Halley, May & Frosch, 2015) by electing more aggressive forms of treatment (see Covelli et al., 2015), even prior to their knowledge of having a diagnosis (for example, 'damage limitation').

Due to the connection that breasts are perceived to share with one another ('a breast connection'), the remaining breast, by association, has turned 'bad' with the potential to be destructive (Parkinson, 2003). Surgical decision making is thus aided by disconnecting from the cognitive and affective meanings that women previously ascribed to their breasts, whilst also recognising that a breast reconstruction would not be the same ('an inferior replica'); a finding also described by Holland, Archer & Montague (2016). Consequently, some women detached from their remaining breast ('a burdensome breast'), including from its sexual meaning, which could be an attempt to prepare for a future cancer 'battle'. This may help women distance themselves from their fear of cancer. However, for others whose fear is overwhelming, the disconnection from their remaining breast could ease their decision to have a CPM.

### **Limitations**

Consistent with an IPA approach, a purposive sample was recruited to ensure homogeneity within participants. Whilst homogeneity was achieved, some differences were noted. This included three women having a previous cancer

diagnosis and one woman having immediate family members with breast cancer. These factors may have altered their degree of risk for contralateral breast cancer. In addition, one interview (Phyllis) was conducted in the presence of the participant's adult daughter. Whilst every effort was made to 'bracket' her daughter's contributions, these would have inevitably shaped her interview.

Women's experiences of having breast cancer and a mastectomy have been found to differ over time (Drageset, Lindstrøm & Underlid, 2016). This study reports on seven women's experiences at a single time point, all of which were within three years of having a mastectomy. Their experiences of worry about cancer recurrence (Hagen et al., 2015) and their decision to have a reconstruction (Fallbjörk, Salander & Rasmussen, 2011) could therefore alter at different stages, especially given that one woman had not completed her treatment. Longitudinal research would be required to identify these changes which could better inform psychological interventions.

### **Clinical implications and future research**

Women's decisions not to have a reconstruction was a choice that was embedded within their personal values. Unlike Reaby (1998), the researcher of the present study did not perceive this decision to reflect the 'easiest' option. However, the prosthesis was found in part, to help women avoid the impact of their changed bodies post-mastectomy. As recommended by NICE (2009) all women with breast cancer should have access to psychological support. For women with one breast, this could help them to have greater insight and an ongoing acceptance of their difficulties. This could improve their quality of life and continued ability to live with one breast.

Six of the seven women in this study were aged over 55, while one, Claire was 46. This sample reflects existing research that describes how women generally over the age of 60 are less likely to undergo a breast reconstruction. However, it is important to consider that these women shared many similarities in regards to their outlook on life and the ways in which they perceived themselves before and after a mastectomy. Such facets were not always

determined by their age or stage of their life. The decision not to have a reconstruction therefore should not just be understood in terms of age alone.

Due to the experiential and idiographic nature of this study, the findings are not generalisable. However, much can be learnt from these women in terms of how they manage a life with one breast and their fear of cancer recurring. Further research with a greater sample size is required to explore how women perceive their remaining breast, specifically amongst women who elect to have a CPM in absence of a risk-reducing benefit. For women electing to have CPM through fear, ACT could be used to help relieve emotional distress that can contribute to symptom reporting and misattribution of such symptoms (Ogden, 2007), that would otherwise perpetuate the fear of cancer returning (Crist & Grunfeld, 2013).

## **Conclusion**

This study reports on the findings of seven women's experiences of living with and managing the imbalance of having one breast. The difficulties that persisted following their diagnosis were more often attributed to the need to look normal to others and to overcome a sense of defectiveness that had been imposed on them through the idealised two-breasted woman. Women managed these impositions by embracing the use of a prosthetic breast, whilst also focusing on aspects of their lives which they valued, over that of having cancer and a changed body image. All women reflected positively on their ability to cope and recognised this as being a source of their strength.

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## Paper 3

### A Feminine Connection: A Reflective Commentary



Word count: 2664

## **Abstract**

This paper provides a reflective commentary on the methodology, ethical challenges, findings and clinical implications from Papers 1 and 2. This is a requirement for the doctorate in Clinical Psychology and is not for the aim of being published. Paper 3 has been written in the first person to reflect the researcher's personal account of conducting clinical psychology research.

## **A Feminine Connection**

### **What is wrong with having just one breast?**

During my first year of doctoral training, I was allocated a placement working within a Psycho-Oncology service. As part of this placement, I was invited to attend routine psychological consultations with women who were electing to have a contralateral mastectomy. Following on from the assessments with women and their expressed desires to either have two breasts or none at all, my supervisor on this placement, Dr Marilyn Owens, queried 'what is so bad with having just one breast?'. At first, I believed it to be 'common sense' to either have two breasts or none. This question challenged my own assumptions and beliefs surrounding women's experiences of breast cancer and what a female body should look like including the meaning behind having symmetrical breasts. It was following this conversation that I went on to construct a thesis driven by this question.

### ***Fighting for the topic***

During discussions with my peers about my research topic, I was confronted with confusion that paralleled my own as to why women would choose to have one breast. This often made me doubt the value of the research and during the planning stages I kept needing to remind myself of the clinical utility of this research. I was later reassured by the interest from the breast nurses and a surgeon at the NHS Trust that supported the recruitment to this study. During a meeting with a nurse and surgeon, the surgeon expressed his own research interest into the expectations that women have when electing a breast reconstruction. He said he believed that women expected a reconstructed breast to look exactly like the one they've lost. I noted that this conversation began to focus on women's decisions to have a reconstruction, rather than on women who choose not to. I found myself once more having to defend my own research focus. After reading about women's experiences in the literature, my fight to defend this research topic seemed to mirror the fight of some women who were choosing not to have a reconstruction. This increasingly reassured me of the value of this research.

### ***A feminine connection***

I have never previously identified myself as a feminist, but since commencing this research, I have been drawn to the literature that identifies the medicalisation of women's health across the lifespan (Conrad, 2007). This has also been emphasised to me through supporting my sister during a planned home birth, and her need to keep her birth plan 'quiet' due to the potential disapproval from others. This has fuelled my passion as a Clinical Psychologist to empower women and the decisions they make.

## **Paper 1: Reconstruction and CPM: Pathways to Normality?**

### ***Reflecting on the process***

I believed this to be a radical piece of a research in a field where CPM and reconstruction are viewed as entirely separate procedures, despite their similarities. I found it striking that risk and survival benefit dominate authors' discourse around CPM, but are largely absent from research exploring decisions for reconstruction. This is despite the fact that neither surgery is without risk and both procedures involve compromising healthy body tissue.

My review question initially attempted to find out how decisions to have elective breast surgery were made by women who had a unilateral mastectomy. This search revealed that women make elective-surgical decisions prior to having their mastectomy; women decide against having one breast before they even experience it. This altered my research focus to how women who have a unilateral breast cancer (and who require a mastectomy) make decisions to have elective surgery. In doing so, I kept my initial search terms given that searching for 'mastectomy' would be inclusive of women with a single side breast cancer.

As part of constructing the search strategy, I felt under pressure to try and find every relevant paper that I could, which ended up being an arduous and extensive task. My experience of this reflected the findings by Neill, Amstrong & Burnett (1998) who stated that information seeking provided a coping strategy for women wanting a reconstruction. For me, this process helped me to manage my fear of failure associated with completing this doctorate. Fortunately, I sought support from my supervisors who were able to offer



reassurance. However, I wondered about the support provided to women who do not elect to have a reconstruction, given that psychological support is predominantly offered to women who wish to undergo this procedure (Rainsbury & Willett, 2012).

### ***Limitations***

Combining decision-making for reconstruction or CPM was a complex task. The research for reconstruction is complicated by participant samples being a mix of women who have and have not had a reconstruction, and who have different diagnoses (for example, unilateral combined with bilateral breast cancer) and breast surgeries (including breast conservation surgery and mastectomy). Similarly, participant samples in studies exploring CPM are mixed with high and low risk women for contralateral breast cancer and also include women who have had a reconstruction. Trying to identify women who share similar decision-making experiences was a significant challenge. In addition, some women choose to have a reconstruction following their CPM and hence can elect to have both surgical procedures rather than one or the other. For this reason, there may be a greater variation in the decisions that women make based on these differences, than those outlined in Paper 1. However, I was reassured by my supervisor, in her role as Chair of the Faculty of Oncology and Palliative Care for the British Psychological Society, that this is in fact the national picture and it contributes to the confusion in developing appropriate decision-making guidelines.

### **Paper 2: “It’s all about a balance...”: Women’s experiences of having one breast**

#### ***Ethical issues***

Identifying women with one breast in the community was far easier than in the published research; a possible indication of their experiences being underrepresented in the existing literature. I was keen to commence my interviews after enduring the bureaucratic nature of the NHS ethical approval process. I was surprised then, that when requesting consent and signposting participants to the information sheet prior to the interviews, that participants were generally not interested in the ethics. Phyllis humorously said “I don’t

care about all of that, ask me what you like love”. However, it was during this same interview that Phyllis described some distressing experiences related to her care in hospital, substantial enough to warrant a complaint. I was pleased that I had provided her with the Patient Advice and Liaison Service number within the participant information sheet, despite her not wishing to act on her concerns.

The ethical process was also reassuring in supporting my transition from clinician to researcher. Women were sharing their personal and often distressing accounts of having breast cancer. I was suddenly faced with the reality that, although I was able to draw upon my clinical skills if necessary, I was not in a position to offer participants psychological therapy. For this reason, I was reassured by the NHS ethical process. This provided me and the participants with a safety net that enabled me to leave the interviews with confidence of their welfare.

### ***Reflecting on process***

Making field notes and transcribing my own interviews enabled me to reflect on one interview at a time. I noted from the first participant that I introduced the topic of her remaining breast over half way through the interview. I appeared to fall into the trap that is so apparent in the research, by focusing on what has been lost and not what remains present. However, my interview style may have been a reaction to the participant’s defence:

*Petra appeared committed to demonstrating her strength to me, to the extent this felt intimidating at times. She quickly dismissed the idea of having thoughts or feelings towards her opposite breast, an idea that she seemed to consider as being weak. She ended the interview stating that I probably wanted someone who was “psychologically suffering”.*

I reflected on Petra’s need to appear strong in relation to her profession as a nurse. This may have been a coping strategy developed from having to prioritise the needs of others over her own. Following this interview, I made a concerted effort to ask about women’s experiences of their opposite breast towards the start of the interview.

I found that once the interview was over, women were interested in my own perspective of having/not having a breast reconstruction. It seemed odd, that irrespective of having cancer, I was still entitled to an opinion on this decision. In this sense, it is being a woman that gives me access to this decision, and not my experience of having cancer. This was noted during the literature review, whereby studies exploring reconstruction did not include women's experience of cancer, which contrasted to research exploring CPM. The topic of reconstruction seems to reinforce the notion of breast cancer as a cosmetic rather than a health crisis (Rubin & Tanenbaum, 2011).

Women in the study demonstrated their array of coping styles. I felt reassured by the women as they described their ability to hold on to their sense of self in spite of their significant physical changes. All of the participants described wearing the prosthesis in public, even if they were comfortable without it at home. I was surprised by the comparison between breast loss to their perceptions of disability, which appeared to connect them to a physical sense of defectiveness. The perceived defectiveness of having one (or no) breasts is perhaps further perpetuated by the National Health Service, whereby reconstruction is promoted, and where CPM is challenged. Sue described being repeatedly asked by her doctor whether she wished to pursue a reconstruction despite her decision against it. It would seem incomprehensible that women would be asked or even encouraged to have a CPM in absence of a medical need. It is not surprising then, that women who make decisions against the norm of having a reconstruction describe themselves as being 'different' to others (see Paper 2).

### ***Limitations***

Due to the subjectivity of Interpretative Phenomenological Analysis, Smith (2011) recommends that data is discussed with other researchers to provide triangulation and reduce bias. Whilst the themes of Paper 2 were clarified with my supervisors, it was not possible to do this in any great depth. Having the availability of a research team or second reviewer, could have strengthened the validity of the themes identified.

Women's curiosity towards my own opinion regarding reconstruction may have been a reflection on our age differences. The experiences which they

agreed to share with me were likely shaped by this difference. I reflected on this with my supervisor, specifically in regards to the difficulty of asking about women's sexual experiences post-mastectomy. I found this topic difficult to approach due to the absence of a perceived neutrality in which a dialogue around sex could be facilitated. I found that women were generally quite dismissive about the impact of their mastectomy on their sex lives. The differences between our ages may have also influenced how women spoke about their remaining breast. To overcome this limitation, an open-ended questionnaire that explored women's sexual experiences after mastectomy may have facilitated a more open conversation.

### **Clinical Implications**

Based on the findings of Paper 1 and 2, Clinical Psychologists have the opportunity to support women to reflect on the meaning they ascribe to their breasts, and the impact that mastectomy has imposed on this meaning. This would be beneficial given that surgical decisions could be made in response to their unknowing disconnection from these meanings. This could subsequently impact on the expectation of the elective surgery and the role women expect the surgery to serve.

Overall, women's decisions not to have a reconstruction should be viewed as making an active choice rather than a 'non-choice' (Holland, Archer & Montague, 2016). Psychological support should be offered to aid this decision, much as women are offered psychological support when electing to have reconstruction or CPM.

### **Future Directions**

There is much curiosity around women electing CPM based on its limited survival benefit. In contrast, there appears little concern about the promotion of reconstruction in absence of a definitive psychosocial benefit. Further research with greater methodological rigour and longitudinal designs are required to investigate the role of reconstruction on body image and quality of life. Similarly, research is required to determine the effect that CPM has on reducing the fear of a cancer recurrence (Beesley, Holcombe & Salmon, 2013) compared with those who do not elect this surgical choice. The outcomes

should also be compared against the use of psychological therapies for the treatment of fear associated with cancer recurrence.

The women in this study described how they had adjusted to the use of their prostheses, though most mentioned their expense and heaviness. More attention should be given to ensuring women are aware of their 'one breasted' options, and the products which are available. This is important given some women elect to have a reconstruction because of their expectations of how they may cope without a reconstruction (Begum, Grunfeld, Ho-Asjoe & Farhadi, 2011).

### **Learning points**

As a psychologist, I am naturally drawn (and trained) to tolerate being in a position of 'unknowing' rather than that of an 'expert'. The unknown position facilitates curiosity and encourages a greater person-centred approach that is so integral to clinical psychology (British Psychological Society, 2009). In contrast, doctoral research requires greater authority and certainty over one's knowledge and interpretation. This position has helped me to have a greater sense of autonomy and self-belief as a researcher and as a clinician. Conducting this research has also encouraged me to work methodically and scientifically, whilst integrating my own reflexivity. By completing this doctoral thesis, I feel I have developed the skills that reflect the cornerstones of being a reflexive-scientist practitioner (Health and Care Professions Council, 2012).

### **Concluding Comments**

As a female, I am subject to being on the receiving end of breast cancer campaigns and have in the past, taken part in various Race for Life events in the support of breast cancer. My position with this movement has been on the periphery of having some knowledge of breast cancer and some experience of what it is like to lose someone to the illness. In effect, I currently have a flexible membership to a club that I might one day have exclusive access to, whether I desire it or not. Despite having more exposure to the positive role that others can offer after having breast cancer, I remain ambivalent towards the authenticity of these connections. The marketing of the campaign itself is also something I fail to connect with. Does losing a breast mean I am required

to connect with all things pink and feminine? I continue to question whether the over-exposure to breast cancer awareness allows women to connect with their own emotional experience of the disease. I also question whether the pink campaign puts femininity at the forefront before women can even question what meaning they ascribe to being and feeling feminine.

It is important that I stipulated that I am no more favourable to one decision than another. I am also immensely aware of the benefits that being a member of 'breast watchers' provides for some women. The overall aim of my empirical paper was to hear the views of women who are underrepresented in breast cancer research. Considerable clinical value can be taken from these women who accept and manage their changed physical female form, whilst deciding against surgery that challenges the norms and pressures of society to look like the 'ideal' female.

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## **Appendices**

### **Paper 1**



## Appendix A

### ***Author Guidelines for Psycho-oncology***

**Manuscript style.** The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. It is not necessary to double-line space your manuscript. There should be a separate title page with full information and another page for an abstract, prior to the Introduction. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Figures should be uploaded as separate figure files.

- During the submission process you must enter the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs.
- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)**
- Enter an **abstract** of up to 250 words for all articles. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work. You **must** submit your abstract according to these headings: objective; methods; results; conclusions.
- Include up to ten **keywords** which **must** contain the words cancer and oncology that describe your paper for indexing purposes.
- All manuscripts must include within the Discussion section a paragraph explaining the **study limitations** and a paragraph explaining the **clinical implications** of the study.
- Research Articles should not exceed 4000 words (including no more than four figures and/or tables) plus up to 40 references. Review papers of up to 6000 words will be considered, with 80 references - authors should contact the Editors for advice. All papers should use the following headings: Background, Methods (including statistical methods), Results, Conclusions. Word counts should include the title page, abstract, main manuscript, tables and figures, but exclude the references.

**Reference style.** All references should be numbered consecutively in order of appearance and should be as complete as possible. In text citations should cite references in consecutive order using Arabic superscript numerals. Sample references follow:

a) *Journal article*

1. King VM, Armstrong DM, Apps R, Trott JR. Numerical aspects of pontine, and inferior olivary to two paravermal cortical zones of the cat cerebellum. *J Comp Neurol.* 1998;39:537-551.

b) *Chapter in a book*

2. Jupiter KC, Ringer DC. Nonhuman Primates. In: Fond MG, Sanders CC, Loewen FM, eds. *Laboratory Animal Medicine*. San Diego: Academic Press; 2002:675–791.

c) *Book*

3. Voet D, Voet JG. *A Population-based Policy and Systems Changed Approach*. New York: John Wiley & Sons; 1990.

d) *Website references*

4. Groove KJ. Primate Factsheets 2010. <http://pin.primates.12345.wisc.edu/factsheets/>. Accessed November 21, 2015.

Journal title abbreviations should conform to the practices of Chemical Abstracts.

**Illustrations.** Upload each figure as a separate file in either .tiff or .eps format, with the figure number and the top of the figure indicated. Compound figures e.g. 1a, b, c should be uploaded as one figure. Tints are not acceptable. Lettering must be of a reasonable size that would still be clearly legible upon reduction, and consistent within each figure and set of figures. Where a key to symbols is required, please include this in the artwork itself, not in the figure legend. All illustrations must be supplied at the correct resolution:

Black and white and colour photos - 300 dpi

**Ethics.** This journal is a member of, and subscribes to the principles of, the [Committee on Publication Ethics \(COPE\)](#). Authors of research papers should provide information about funding, a Conflict of Interest statement, the name and reference number of the Research Ethical Committee, and (if the paper is a clinical trial) details of trial registration, including the registration number and name of the registry. All of these declarations should be in the main paper itself, not in a separate document. If authors include named individuals in the Acknowledgements they must confirm that they have approval from those individuals in their covering letter.

## **Appendix B**

### ***Search Terms***

The following terms were searched in EBSCO, Web of Science and Cochrane Library. All searches were conducted on 14.12.16.

EBSCO search - All terms were searched using the 'Abstract' option.

Web of Science - All terms were searched using the 'Topic' option.

Cochrane Library - All terms were search using the 'Abstract/topic/title' option.

"unilateral mastectomy" OR mastectomy OR "simple mastectomy" OR "total mastectomy"

AND

reconstruct\* OR "contralateral prophylactic mastectomy" OR "contralateral mastectomy" OR "contralateral risk reducing mastectomy" OR "risk reduc\*" OR "breast reconstruction"

AND

experienc\* OR "decision making" OR decision\* OR decid\* OR choice\* OR reason\*

AND NOT

"genetic testing" OR "prophylactic bilateral mastectomy" OR "BRCA 1" or "BRCA 2" OR "bilateral risk-reducing mastectomy" OR "bilateral prophylactic mastectomy" OR "partial mastectomy" OR "breast conservation"

## **Appendix C**

### ***Excluded Topics using Web of Science Database***

- Physics applied
- Obstetrics gynaecology
- Paediatrics
- Otorhinolaryngology
- Radiology
- Nuclear medicine
- Medical imaging
- Public environmental occupational health
- Materials science biomaterials
- Infectious diseases
- Integrative complementary medicine
- Cardiac cardiovascular systems
- Imaging science photographic technology
- Urology nephrology
- Hematology
- Respiratory system
- Gastroenterology hepatology
- Genetics heredity
- Pathology
- Engineering multidisciplinary
- Optics
- Orthopedics
- Information science library
- Dermatology
- Business
- Pharmacology pharmacy
- Biochemistry molecular biology
- Anesthesiology
- Biochemical research methods
- Engineering biomedical

## Appendix D

### ***Crude Categories of Excluded Articles n=1542***

<p>Not related to decision-making = 1415</p>	<ul style="list-style-type: none"> <li>• Reviews /systematic reviews/meta-analyses/ Randomised control trial = 75</li> <li>• Case study = 15</li> <li>• Supplement articles/editorials = 13</li> <li>• Study Protocol = 5</li> <li>• Surgeon perceptions/influences = 19</li> <li>• Surgery methods and aesthetic surgery/functional outcomes = 909</li> <li>• Survival rates, trends in surgery types, variations in surgery = 120</li> <li>• Regression studies = 31</li> <li>• Comparison studies = 20</li> <li>• Economic cost of surgery = 10</li> <li>• The impact of pain = 3</li> <li>• Health behaviours/health factors = 3</li> <li>• Genetic testing/familial risk/hereditary/BRCA studies = 58</li> <li>• Impact of radiotherapy/chemotherapy = 41</li> <li>• Use of MRI = 10</li> <li>• Claims = 2</li> <li>• Role of multidisciplinary teams = 3</li> <li>• Intervention studies = 3</li> <li>• Quality of life/satisfaction/body image/patient reported outcomes = 43</li> <li>• History of reconstruction = 2</li> <li>• Age related = 2</li> <li>• Qualitative = 26</li> <li>• Not oncology = 2</li> </ul>
<p>Decision-making = 127</p>	<ul style="list-style-type: none"> <li>• Review = 13</li> <li>• RCT = 3</li> <li>• Case study = 3</li> <li>• Mixed methods = 2</li> <li>• Guidelines = 1</li> <li>• Involves oophorectomy = 1</li> <li>• Supplement/editorial papers = 4</li> <li>• Partial/breast conservation = 6</li> <li>• No reconstruction = 3</li> <li>• Not oncology = 2</li> <li>• The role of the internet = 1</li> <li>• Quantitative studies = 88 <ul style="list-style-type: none"> <li>○ Factors influencing/predictors/social factors = 43</li> <li>○ Informational needs of patients = 4</li> <li>○ Comparison studies = 11</li> <li>○ Intervention studies = 1</li> <li>○ Decision regret = 7</li> <li>○ Decision-making tool = 7</li> <li>○ Quality of life = 4</li> <li>○ Satisfaction = 3</li> <li>○ Decision making styles = 1</li> <li>○ Surgical methods = 2</li> <li>○ Survival outcomes = 1</li> <li>○ Family history/genetic risks = 4</li> </ul> </li> </ul>

## Appendix E

### *Reasons for Articles Excluded n=8*

Reference	Reason for exclusion
	<b>-Some focus on decision making</b>
1. Fallbjörk, U., Frejeus, E., & Rasmussen, B. H. (2012). A preliminary study into women's experiences of undergoing reconstructive surgery after breast cancer. <i>European Journal of Oncology Nursing</i> , 16, 220-226.	This article from Sweden focuses on women's experiences of having reconstruction. Deciding to have reconstruction features within this study but it is not the primary aim of the research.
2. Hill, O., & White, K. (2008). Exploring women's experiences of TRAM flap breast reconstruction after mastectomy for breast cancer. <i>Oncology Nursing Forum</i> , 35, 81-88.	The aim of this study was to explore women's experiences of TRAM flap reconstruction. Decisions regarding breast reconstruction were explored but these were asked alongside the impact of breast cancer and having a mastectomy.
3. Fang, S., Balneaves, L. G., & Shu, B. (2010). "A struggle between vanity and life": The experience of receiving breast reconstruction in women of Taiwan. <i>Cancer Nursing</i> , 33, 1-11.	This study explores the experiences of Taiwanese women who have undergone breast reconstruction. Questions were asked about how women made the decision to have surgery but decision-making was not the primary aim.
4. Murray, C. D., Turner, A., Rehan, C., & Kovacs, T. (2015). Satisfaction following immediate breast reconstruction: Experiences in the early post-operative stage. <i>British Journal of Health Psychology</i> , 20, 579-593	This study aimed to explore women's experiences of immediate reconstruction shortly following surgery with the objective to determine the factors influencing patient satisfaction. Decision making features throughout this article but is not the primary focus of the study.

Reference	Reason for exclusion
	<b>Heavier focus on decision making</b>
5. Fallbjörk, U., Salander, P., & Rasmussen, B. H. (2012). From "no big deal" to "losing oneself": Different meanings of mastectomy. <i>Cancer Nursing</i> , 35, 41-48.	This study explores how women describe having a mastectomy and the impact it has on their lives, which helps the authors to contextualise women's reflections on having reconstruction. Reasons for having and not having reconstruction did heavily feature within the results but this was not the primary aim of the article.
6. Potter, S., Mills, N., Cawthorn, S., Wilson, S., & Blazeby, J. (2013). Exploring inequalities in access to care and the provision of choice to women seeking breast reconstruction surgery: A qualitative study. <i>British Journal of Cancer</i> , 109, 1181-1191.	The aim of this study was to explore patients' and health professional's experiences of provision of choice in NHS services relating to breast reconstruction. The objective was to determine what choices and barriers are in place in respect to having a breast reconstruction.
7. Truelsen, M. (2003). The meaning of 'reconstruction' within the lived experience of mastectomy for breast cancer. <i>Counselling &amp; Psychotherapy Research</i> , 3, 307-314.	This study explored women's experiences of having a mastectomy and either choosing to have or not have breast reconstruction. However, the article did not meet the quality requirements as outlined by the CASP quality tool and considerable ethical concerns were identified. Specifically, in regards to the role of the researcher and approach to participant recruitment.
8. Wolf, L. (2004). The information needs of women who have undergone breast reconstruction. Part 1: decision-making and sources of information. <i>European Journal of Oncology Nursing</i> , 8, 211-223.	Decision-making for breast reconstruction was explored in the context of the information needs of women undergoing this surgery. This article focuses on the relevance and timing of information that is appropriate to support women's decisions.

## Appendix F

### ***Quality Scoring Framework using a Critical Appraisal Skills Programme Tool***

KW	Not Fulfilled 0	Partially fulfilled 1	Completely fulfilled 2	JW	Not sure 0	Partially fulfilled 1	Completely fulfilled 2
1. Statement of aims				1. Statement of aims			
2. Appropriate method				2. Appropriate method			
3. Research design appropriate				3. Research design appropriate			
4. Appropriate recruitment?				4. Appropriate recruitment?			
5. Data collection appropriate?				5. Data collection appropriate?			
6. Researcher's role				6. Researcher's role			
7. Ethical issues addressed?				7. Ethical issues addressed?			
8. Rigorous data analysis?				8. Rigorous data analysis?			
9. Clear statement of findings				9. Clear statement of findings			
10. Valuable?				10. Valuable?			
<b>Scores</b>				<b>Scores</b>			
<b>Total Score</b>				<b>Total Score</b>			



**Appendix G**  
***Participant Characteristics***

***Recon = Reconstruction IR = Immediate Reconstruction DR = Delayed Reconstruction***

<b>Author</b>	<b>Cancer stage</b>	<b>Age (M/Range)</b>	<b>Time since surgery</b>	<b>Surgery type</b>	<b>Marital status</b>	<b>Education</b>	<b>Ethnicity</b>
Beesley, Holcombe, Brown & Salmon, 2013	Unknown	47 (24-68)	Mean of 3 years since last therapeutic surgery.	Mastectomy = 52/60  Bilateral mastectomy = 4  54 patients went on to have CPM, 3 awaiting the decision to have CPM.	Unknown for entire sample	Unknown	Unknown
Begum, Grunfeld, Ho- Asjoe & Farhadi, 2011	Unknown	48 (38-61)	12.5 months (4-35 months) since recon	IR= 12 DR = 9  All autologous reconstruction	Married = 12 Divorced = 3 Single = 6	13/21 had obtained degree level or higher	Caucasian =13 Black African =6 Black Caribbean =1 White Portuguese =1

Author	Cancer stage	Age (M/Range)	Time since surgery	Surgery type	Marital status	Education	Ethnicity
Boehmer, Linde & Freund, 2007	No recon: Stage 0= 2 Stage 1 = 1 Stage 2 =3 Unknown = 2  Recon:  Stage 0 = 2 Stage 1= 1 Stage 2=3 Unknown = 2	No recon: 50.7 (43-61)  Recon: 47.3 (41-53)	Unknown	TRAM Flap = 3  Saline implant = 5	Unknown	No recon: College = 4 College grad = 3  Recon: College = 5 College grad = 3	No recon: Caucasian = 7  Recon: African American = 1 Caucasian = 7
Covelli et al., 2015	Stage 1 = 15 Stage 2 = 14	Unilateral mastectomy = 56 (42-84)  CPM = 37-69 M46	9-12 months from either having unilateral mastectomy or UM+CPM	Unilateral mastectomy with recon = 3  Contralateral mastectomy with recon = 8  Unilateral mastectomy no recon = 6  Contralateral mastectomy no recon = 8	Unknown	Unknown	Unknown

Author	Cancer stage	Age (M/Range)	Time since surgery	Surgery type	Marital status	Education	Ethnicity
Harcourt & Rumsey, 2004	Unknown	55 (29-78)	Unknown	Mastectomy alone = 56  Immediate reconstruction = 37	No recon  Married = 39/56  Recon group Married = 26/37	No recon  Post-secondary education = 25  Recon group  Post-secondary education = 18	Unknown
Jerome- D'Emilia, Suplee, Boiler & D'Emilia, 2015	0 = 2  1 = 7  2 = 9  3 = 5	46 (30-68)  (Age at diagnosis = M44.1)	1-3 years of diagnosis and treatment	All women underwent bilateral mastectomy and bilateral reconstruction.	Single = 1  Married = 20  Divorced = 2	Some college = 7  College graduate = 12  Graduate school = 4	Caucasian = 22  African American = 1
Lee, Hultman & Sepucha, 2010	History of early stage breast cancer	Unknown	Recruitment within 5 years of women having a mastectomy.	Women who either opted to have reconstruction or not. No further details given.	Unknown	Unknown	Unknown
Neill, Armstrong & Burnett, 1998	Not stated	48 (39-61)	Unknown	IR = 10 DR = 1 • TRAM flap = 6 • Saline = 4 • Silicone = 1	Married = 8 Divorced = 1 Single = 2	Unknown	White = 8 African American = 2 Asian American = 1

Author	Cancer stage	Age (M/Range)	Time since surgery	Surgery type	Marital status	Education	Ethnicity
Reaby, 1998	Not stated	Prosthesis group = M 63  Recon =M 49.5	Between 2 and 7 years since diagnosis.  (M = 3.2 years)	Breast recon = 31  No recon = 64  Type of reconstruction not described.	Married = 67 (70% of the sample)  No further information provided.	unknown	White = 76 (80% of the sample)  No further information given.
Rendle, Hally, May & Frosch, 2015	Stage  0 = 1 1 = 6 2 = 1 3 = 1	M48.1  No further details given	Unknown	All underwent Contralateral mastectomy.	Married/partnere d = 7  Separated/divorc ed =2	Graduate degree = 4 College graduate =2 Some college = 2 High school =1	Asian = 2  Caucasian = 6  Hispanic= 1
Rubin, Chavez, Alderman & Pusic, 2013	Unknown	Age at mastectomy 52.7(26-78)	23 women had recon in the last 3 years  Mastectomy - 1 month-8 years	Recon = 12  No recon = 15	Single = 13 Married = 10 Widowed = 3 Unknown = 1	Unknown	African American women

Author	Cancer stage	Age (M/Range)	Time since surgery	Surgery type	Marital status	Education	Ethnicity
Rubin & Tanenbaum, 2011	Stage: 0-2= 9 >3 =3 Never informed = 1	(29-56)  No further details given.	7-82 months since mastectomy.	Recon = 11  No recon =2	Long-term relationship = 7  Single = 5  Divorced = 1	All highly educated, holding some college education and 8 holding degree or graduate education.	Caucasian = 12  Unknown =1

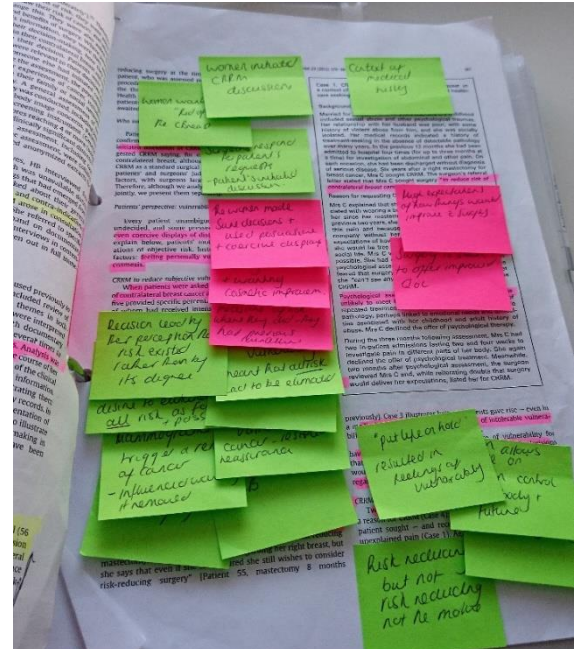
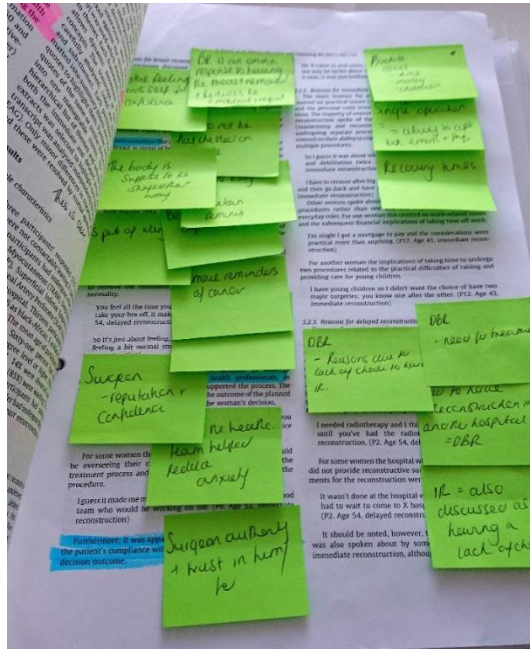
## Appendix H

### *Thematic Analysis: Method for Qualitative Synthesis*

*Adapted from Thomas & Harden (2008)*

Stage	Description
1. Free line-by-line coding	This involves the translation of concepts between each article to develop a list of codes. Multiple codes can be used to describe single sentences. Ensure developing codes reflect the text description as closely as possible.
2. Organising free codes to develop descriptive themes	Organise the codes into themes looking for those that both support and refute the developing themes.
3. Develop analytical themes	Involves going beyond the developing themes and applying them to answer the review question.

### ***Examples of Coding Strategy***

[illegible]

**Appendix J**  
***List of Codes and Supporting Examples***

<b>Descriptive codes</b>	<b>Evidence (Descriptive statements and quotes)</b>	<b>Article</b>
<b>The initiation of the decision</b>	<i>Because he said to me, do you want to reconstruct it and I said no, I want want to get rid of it [first]</i> ".	Harcourt & Rumsey, 2004
	Women argued <i>sensibly and cogently</i> .	Beesley, Holcombe & Salmon, 2013
	CPM discussion was always initiated by the patient.	Covelli et al., 2015
	Reconstruction was initiated by the surgeon.	Harcourt & Rumsey, 2004
<b>Reconstruction and pressure</b>	Implicit and explicit pressure to have reconstruction with clinicians framing it to be a 'natural' step in treatment following mastectomy.	Rubin & Tanenbaum, 2011
	Assumptions were made about what the women wanted – information was selectively offered to the women.	Rubin & Tanenbaum, 2011
	You have to justify to opt out of surgery, reasons for opting in were viewed as self-evident, particularly those judged to be good candidates.	Rubin & Tanenbaum, 2011
<b>Just do it – reconstruct or get rid</b>	<i>Get rid of them.</i>	Beesley, Holcombe & Salmon, 2013
	<i>Just do it</i> (have reconstruction).	Begum et al., 2011.



	<i>We'll just do this and get it done and then close this chapter.</i>	Jerome-D'Emilia, Suplee, Boiler & D'Emilia, 2015
	<i>I was just like, I'm done, take them both.</i>	Rendle, Halley, May & Frosch, 2015
<b>Control cancer</b>	Move on, regain control over body and future.	Beesley, Holcombe & Salmon, 2013
	Electing to have a bilateral mastectomy was a means of taking control.	Jerome-D'Emilia, Suplee, Boiler & D'Emilia, 2015
	CPM means removing future worry.	Rendle, Halley, May & Frosch, 2015
	Reconstruction put women in the power seat – it enables them the choice of when and where to talk about their cancer history.	Rubin & Tanenbaum, 2011
<b>Vulnerable feelings</b>	Intolerable vulnerability and vulnerability that cannot be reassured.	Beesley, Holcombe & Salmon, 2013
	The choice to be flat (CPM) gives peace of mind and symmetry.	Covelli et al., 2015
	The difference in breasts reminds you of being a victim (i.e. after having unilateral mastectomy).	Rendle, Halley, May & Frosch, 2015
	Despite reassurances that a second cancer could be detected with increased surveillance, women were reluctant not to have CPM based on not wanting to re-live being told about having cancer.	Jerome-D'Emilia, Suplee, Boiler & D'Emilia, 2015

<b>Subjective feelings of risk</b>	Mammograms create worry and are an inconvenience – the anticipation of worry led some women to have CPM.	Rendle, Halley, May & Frosch, 2015
	Benign pain increases subjective risk.	Beesley, Holcombe & Salmon, 2013
	All or nothing approach to risk.	Beesley, Holcombe & Salmon, 2013
	Disproportionate concerns about breast cancer returning - not being worried about the treated side but the other side.	Covelli et al., 2015
	<i>I didn't want to consider silicone because the safety is somewhat questionable.</i>	Lee, Hultman & Sepucha, 2010
	Women worried about the implant interfering with the detection of the cancer a future cancer.	Rubin, Chavez, Alderman & Pusic, 2013
<b>Life is on hold versus getting on</b>	<i>Put life on hold</i>	Beesley, Holcombe & Salmon, 2013
	'Getting life back' was the prevailing theme of choosing reconstruction, which also involved seeking information and talking it over. Women described wanting to get back to a life they had previously.	Neill, Amstrong & Burnett, 1998
	CPM means not having to have other treatments and getting it done.	Rendle, Halley, May & Frosch, 2015

	Reconstruction gives you your life back.	Rubin, Chavez, Alderman & Pusic, 2013
<b>Need for Symmetry</b>	The need for breast symmetry.	Beesley, Holcombe & Salmon, 2013
	Large breasted women feared being unbalanced.	Boehmer, Linde & Freund, 2007
	Choice to have UM and CPM were due to symmetry – trying to match both breasts by having both reconstructed.	Covelli et al., 2015
	The choice to be flat (CPM) which gives peace of mind and symmetry.	Covelli et al., 2015
	A body is supposed to be symmetrical, it will look lopsided.	Neill, Armstrong & Burnett, 1998
<b>Negative feelings towards self and wanting to look like a woman</b>	Actual or expected feelings of having low confidence and negative feelings towards the self (reason for reconstruction).	Begum et al., 2011.
	Some women described feeling complete by having two breasts again.	Boehmer, Linde & Freund, 2007
	<i>I want to feel like a woman again</i>	Covelli et al., 2015
	Resistance is harder to not choose reconstruction (despite images of one breasted warriors) and again this then turns into feelings of inadequacy for some women because they did not choose that option.	Rubin & Tanenbaum, 2011
<b>Procedures and recovery</b>	“So I guess it was about whether I wanted to go through the pain and deliberation twice instead of once”.	Begum et al., 2011.

	<i>It takes a long time to recover, to go back and have another procedure... (reason for immediate reconstruction).</i>	Begum et al., 2011.
	<i>She didn't want reconstruction; we sort of agonized through that one... but the options weren't realistic for her</i>	Boehmer, Linde & Freund, 2007
	CPM allows you to finish treatment. Without CPM it would be a continuous worry.	Rendle, Halley, May & Frosch, 2015
	Surgery/ reconstruction involves further cutting, pain and more recovery, more pain and no guarantees it will work out.	Rubin, Chavez, Alderman & Pusic, 2013
<b>Trust in the healthcare team</b>	Trust in the surgeon and their reputation for doing breast reconstruction was an influencing factor.	Begum et al., 2011.
	The roles of trust and power from the surgeon are very important. Breast nurses are very important.	Reaby, 1998
	A lack of trust in the screening equipment led to making a decision to have CPM.	Rendle, Halley, May & Frosch, 2015
	Risk of implants rupturing etc.	Rubin & Tanenbaum, 2011
	<i>Being black...we don't trust the medical profession. We figure they use us as guinea pigs.</i>	Rubin, Chavez, Alderman & Pusic, 2013
<b>Elective surgery is an emotional</b>	Reconstruction is an emotional response to having the breast removed and the woman's belief about what it would be like to live without a breast.	Begum et al., 2011.

<b>response to mastectomy/cancer</b>	Reconstruction reduces the emotional response to having a single breast	Begum et al., 2011.
	The prosthesis does not allow you to cope with breast loss	Reaby, 1998
<b>Breast reconstruction maintains body image and femininity</b>	Reconstruction helps to maintain a positive body image and maintain femininity.	Begum et al., 2011.
	“Otherness” was noted in context of health providers – discrepancy of values and body image with mainstream society. Lesbians have different views about body image.	Boehmer, Linde & Freund, 2007
	Choosing autologous reconstruction – it’s more natural and droops more naturally.	Lee, Hultman & Sepucha, 2010
<b>(Social) perceptions of female body image</b>	<i>An adult woman should have both breasts.</i>	Begum et al., 2011.
	Breast size featured in the decisions of whether to have or not have reconstruction due to the visibility in the difference between breasts.	Boehmer, Linde & Freund, 2007
	<i>Reconstruction helps you to deal with the outside world</i>	Lee, Hultman & Sepucha, 2010
	Comfort with social self was threatened by physical changes.	Neill, Armstrong & Burnett, 1998
<b>Restore normalcy</b>	<i>So it’s just about feeling, just kind of more normal, feeling a bit normal straight away (immediate reconstruction).</i>	Begum et al., 2011.
	reconstruction made things easier and allowed me to return to what I was.	Reaby, 1998
	Reconstruction is about looking normal.	Rubin, Chavez, Alderman & Pusic, 2013

<b>Practicalities of having elective surgery</b>	Reasons to have immediate reconstruction were based on practical issues: money, children and time – one single operations costs less.	Begum et al., 2011.
	CPM means not having to have other treatment and getting it done.	Rendle, Halley, May & Frosch, 2015
<b>Not being aware of reconstruction</b>	<i>I was blind as far as reconstruction was concerned – I didn't even know it existed.</i>	Harcourt & Rumsey, 2004
	<i>I didn't know much about reconstruction, because when the doctor tried to explain it I just left it up to him, I know it was the only thing that I could live with. I didn't care about complications or risks.</i>	Reaby, 1998
<b>Information as overwhelming</b>	You have to be careful what you search for when going online.	Jerome-D'Emilia, Suplee, Boiler & D'Emilia, 2015
	There are multiple sources of information available – women who have had a reconstruction, physicians, support groups, family and friends.	Neill, Armstrong & Burnett, 1998
	Lots of information can feel overwhelming.	Harcourt & Rumsey, 2004
<b>Information seeking as a way of coping</b>	Talking it over enabled women to clarify their thoughts and reinforce their decision. Talking to others was affirming.	Neill, Armstrong & Burnett, 1998
	Collecting evidence helped to know how to feel and to react.	Jerome-D'Emilia, Suplee, Boiler & D'Emilia, 2015
	Information is assimilated based on the personal needs of the woman.	Neill, Armstrong & Burnett, 1998

<b>Hide cancer</b>	The decision to have reconstruction is about covering up cancer.	Boehmer, Linde & Freund, 2007
	<i>If people think you are terminally ill then they will think of you differently – they know it could reoccur – so I decided not to tell anyone.</i>	Neill, Amstrong & Burnett, 1998
<b>Thinking about the future</b>	Thinking about partners in the future lead to decing to have reconstruction.	Boehmer, Linde & Freund, 2007
	CPM means never having to go through it again.	Covelli et al., 2015

## Appendix K

### *Thematic Synthesis*





## **Appendices**

### **Paper 2**

## Appendix L

### ***Author Guidelines for submission to the Journal of Psychology and Health***

#### Preparing your paper

##### *Structure*

Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

##### *Word limits*

Please include a word count for your paper.

A typical manuscript for this journal should be no more than 30 pages; this limit includes tables, references, figure captions, endnotes.

##### *Style guidelines*

Please use British spelling style consistently throughout your manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

##### *Formatting and templates*

Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting templates.

##### *References*

Please use this [reference style guide](#) when preparing your paper. An [EndNote output style](#) is also available to assist you.

##### *Checklist: what to include*

1. **Author details.** Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the title page. Where available, please also include [ORCID identifiers](#) and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. [Read more on authorship](#).
2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): Objective, Design, Main Outcome Measures, Results, Conclusion. Read tips on [writing your abstract](#).
3. **Graphical abstract** (Optional). This is an image to give readers a clear idea of the content of your article. It should be a maximum width of 525 pixels. If your image is narrower than 525 pixels, please place it on a white background 525 pixels wide to ensure the dimensions are

maintained. Save the graphical abstract as a .jpg, .png, or .gif. Please do not embed it in the manuscript file but save it as a separate file, labelled GraphicalAbstract1.

4. You can opt to include a **video abstract** with your article. [Find out how these can help your work reach a wider audience, and what to think about when filming.](#)
5. 3-6 **keywords**. Read [making your article more discoverable](#), including information on choosing a title and search engine optimization.
6. **Funding details**. Please supply all details required by your funding and grant-awarding bodies as follows:  
*For single agency grants:* This work was supported by the [Funding Agency] under Grant [number xxxx].  
*For multiple agency grants:* This work was supported by the [funding Agency 1]; under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx].
7. **Disclosure statement**. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. [Further guidance on what is a conflict of interest and how to disclose it.](#)
8. **Geolocation information**. Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and [make your article more discoverable to others](#).
9. **Supplemental online material**. Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about [supplemental material and how to submit it with your article](#).
10. **Figures**. Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for color, at the correct size). Figures should be saved as TIFF, PostScript or EPS files. More information on [how to prepare artwork](#).
11. **Tables**. Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
12. **Equations**. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about [mathematical symbols and equations](#).
13. **Units**. Please use [SI units](#) (non-italicized).

## Appendix M

### *Independent Peer Review Approval from the University of Staffordshire*



#### INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Researcher Name Katherine Williams

Title of Study Women's experience of unilateral breast mastectomy without reconstruction

Award Pathway Professional Doctorate Clinical Psychology

Status of approval: Approved

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

#### Action now needed:

You must now apply to the Local NHS Research Ethics Committee (LREC) for approval to conduct your study. You must not commence the study without this second approval.

Please forward a copy of the letter you receive from the LREC to Karen Simpson at the Science Centre as soon as possible after you have received approval.

Once you have received LREC approval you can commence your study. You should be sure to do so in consultation with your supervisor.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

When your study is complete, please send the Faculty ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

*E. H. Boath*

Signed: Dr E Boath  
Chair of the Faculty of Health Sciences IPR Panel

Date: 17<sup>th</sup> December 2015

## Appendix M (Continued)

### Confirmation of Liability Insurance from Staffordshire University



#### Certificate of Employers' Liability Insurance(a)

(Where required by regulation 5 of the Employers' Liability (Compulsory Insurance) Regulations 2008 (the Regulations), a copy of this certificate must be displayed at all places where you employ persons covered by the policy or an electronic copy of the certificate must be retained and be reasonably accessible to each employee to whom it relates).

Policy No. NHE-02CA03-0013  
1. Name of policyholder Staffordshire University  
2. Date of commencement of insurance policy 01 August 2015  
3. Date of expiry of insurance policy 31 July 2016

We hereby certify that subject to paragraph 2:

1. The policy to which this certificate relates satisfies the requirements of the relevant law applicable in Great Britain, Northern Ireland, the Isle of Man, the Island of Jersey, the Island of Guernsey and the Island of Alderney (b)
2. (a) the minimum amount of cover provided by this policy is no less than £5 million (c)

Signed on behalf of Zurich Insurance plc (Authorised Insurer).

Signature

*S. Lewis*

Stephen Lewis

Chief Executive Officer, Zurich Insurance plc (UK Branch)

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#### Notes

- (a) Where the employer is a company to which regulation 3(2) of the Regulations applies, the certificate shall state in a prominent place, either that the policy covers the holding company and all its subsidiaries, or that the policy covers the holding company and all its subsidiaries except any specifically excluded by name, or that the policy covers the holding company and only the named subsidiaries.
- (b) Specify applicable law as provided for in regulation 4(6) of the Regulations.
- (c) See regulation 3(1) of the Regulations and delete whichever of paragraphs 2(a) or 2(b) does not apply. Where 2(b) is applicable, specify the amount of cover provided by the relevant policy.

Authorised by the Central Bank of Ireland and subject to limited regulation by the Financial Conduct Authority. Details about the extent of our regulation by the Financial Conduct Authority are available from us on request.

## Appendix M (Continued)

### Confirmation of Liability Insurance from Staffordshire University



To Whom It May Concern

Our ref: SN/IND

13 July, 2015

Zurich Municipal Customer: Staffordshire University

This is to confirm that Staffordshire University have in force with this Company until the policy expiry on 31 July 2016 Professional Negligence Insurance incorporating the following essential features:

Policy Number: NHE-02CA03-0013

Services covered: The Services

Limit of Indemnity: £ 5,000,000 any one claim and *in the aggregate for all claims* first made against the Insured and notified to Zurich Municipal during the period of insurance

Excess : £ 5,000 any one claim

Retroactive Date: 05 March 2003

#### Exclusions

Standard insurance market exclusions apply, notably exclusion of Pollution other than sudden and accidental; punitive or exemplary damages; express warranties or guarantees; claims the cause of which occurred prior to the Retroactive Date.

*This is a brief summary and the full policy should always be referred to for exact details of cover.*

Yours faithfully

A handwritten signature in black ink, appearing to read 'Nigel Rait'.

Underwriting Services  
Zurich Municipal  
Farnborough

Zurich Municipal  
Zurich House  
2 Oxleygate Way  
Farnborough  
GU14 6GB

Telephone 0870 3418050

Direct Phone: 01252 382849  
Direct Fax: 01252 375885  
E-mail:  
Victoria.Stockley@uk.zurich.com

Communications will be monitored  
regularly to improve our service and  
for security and regulatory purposes

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UK branch registered in England and Wales  
Registration No. 8879865.

UK Branch Head Office: The Zurich Centre,  
2400 Parkway, Whiteley, Fareham,  
Hampshire PO15 7JZ

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the extent of our regulation by the Financial  
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request.

100021440-0001-0001-0001

## Appendix M (Continued)

### Confirmation of Liability Insurance from Staffordshire University



To Whom It May Concern

Our ref: SN/IND

13 July, 2015

Zurich Municipal Customer: Staffordshire University

This is to confirm that Staffordshire University have in force with this Company until the policy expiry on 31 July 2016 Insurance incorporating the following essential features:

**Policy Number:** NHE-02CA03-0013

**Limit of Indemnity:**

**Public Liability:** £ 25,000,000

**Products Liability:** £ 25,000,000

**Pollution:**

any one event  
for all claims in the  
aggregate during  
any one period of  
insurance  
any one event  
inclusive of costs

**Employers' Liability:** £ 25,000,000

**Excess:**

**Public Liability/Products Liability/Pollution:** £ 1,000 any one event

**Employers' Liability:** Nil any one claim

**Indemnity to Principals:**

Covers include a standard Indemnity to Principals Clause in respect of contractual obligations.

**Full Policy:**

The policy documents should be referred to for details of full cover.

Yours faithfully

Underwriting Services  
Zurich Municipal  
Farnborough

Zurich Municipal  
Zurich House  
2 Gosport Way  
Farnborough  
Hampshire  
GU14 6QD

Telephone: 0870 241 8090  
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CONFIDENTIAL (PAGE 002)

## Appendix N

### ***NHS Research Ethics Committee Confirmation***



## ***Health Research Authority***

### **West Midlands - Black Country Research Ethics Committee**

Royal Standard Place  
Nottingham  
NG1 6PS

24 May 2016

Mrs Katherine Williams  
Trainee Clinical Psychologist  
South Staffordshire and Shropshire NHS Trust  
Trust HQ, St George's Hospital  
Corporation Street  
Stafford  
ST16 3SR

Dear Mrs Williams

Study title:	How do women experience having one breast following simple mastectomy without reconstruction? A phenomenological study.
REC reference:	16/WM/0141
IRAS project ID:	191907

Thank you for your letter of 13 May 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Georgia Copeland , [nrescommittee.westmidlands-blackcountry@nhs.net](mailto:nrescommittee.westmidlands-blackcountry@nhs.net).

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Conditions of the favourable opinion**



The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [Evidence of sponsor Insurance]		04 February 2016
Interview schedules or topic guides for participants [Interview topic guide]	1	25 January 2016
IRAS Checklist XML [Checklist_08032016]		08 March 2016
IRAS Checklist XML [Checklist_03052016]		03 May 2016
IRAS Checklist XML [Checklist_13052016]		13 May 2016
Letter from sponsor [Ethics agreement from University]		17 December 2015
Letters of invitation to participant [Expression of Interest letter]	2	18 April 2016
Non-validated questionnaire [Descriptive Information questionnaire]	1	25 January 2016
Other [M Owens CV]	1	01 April 2016
Other [Cover letter for REC]		13 May 2016
Participant consent form [Consent form]	1	25 January 2016
Participant information sheet (PIS) [PIS ]	7	18 April 2016
REC Application Form [REC_Form_03032016]		03 March 2016
Research protocol or project proposal		18 April 2016
Summary CV for Chief Investigator (CI) [CV for CI]		25 January 2016
Summary CV for student [CV for student/CI]		25 January 2016
Summary CV for supervisor (student research) [CV for Academic Supervisor]		25 January 2016

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document '*After ethical review – guidance for researchers*' gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

16/WM/0141
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Please quote this number on all correspondence
--

With the Committee's best wishes for the success of this project.

Yours sincerely



**Dr Hilary Panlagua**  
Chair

Email: [nrescommittee.westmidlands-blackcountry@nhs.net](mailto:nrescommittee.westmidlands-blackcountry@nhs.net)

Enclosures:                      \*After ethical review – guidance for researchers\*

Copy to:                          Dr Elizabeth Boath

*MS Marion Adams, Research & Innovation/Clinical Trials Manager, The Shrewsbury and Telford Hospital NHS Trust*

## Appendix O

### *Research and Development Approval from Site 1*

Dr  
Dr

Fax 01743 482440

Mrs Katherine Williams  
Trainee Clinical Psychologist  
School of Psychology, Sport and Exercise  
Staffordshire University, College Road  
Stoke on Trent  
ST4 2DE

R&I Ref: KWILL01

25/07/2016

Dear Mrs Williams,

Re: How do women experience having one breast following simple mastectomy without reconstruction? A phenomenological study

REC No: 16/WM0141  
IRAS REF: 191907

Total Recruitment Target: 8

We have now received all the necessary paperwork for the above research, as listed on page 2. This letter gives this Trust's approval for your research.

Your research activity is now covered by NHS indemnity as set out in HSG(95)48. Your local reference number with us is Ref :KWILL01 which should be quoted in any correspondence with this office.

#### Conditions of approval:

- Prior to approaching your first patient, please ensure that you receive final confirmation from the sponsor that you are able to commence recruitment.
- Once you have recruited your first patient please inform the R&I office and a member of the team will monitor your study.
- Compliance with the Research Governance Framework and Data Protection legislation.

Trust web site: [www.safh.nhs.uk](http://www.safh.nhs.uk)

Trust Approval Letter - Version Feb 2013



Page 1 of 3

- Inform the R&I Office of any significant protocol violations.
- Forward copies of any external or internal monitoring reports for the study to the R&I office.
- Send into the R&I office, monthly updates on patients recruited within the study, and formal notification of study completion or termination.
- Inform this office of any amendments to the study. Any changes to the study must first be notified to the R&I department, before being implemented at site.
- Anyone working on the study must have received GCP training within the past 2 years and keep it updated.
- When your study has finished provide information to the R&I department of any resulting publications for our records.

The Trust wishes you every success with your research.

Yours sincerely




cc: Sister Helen Moore Trust Lead Research Nurse; Dr Elizabeth Beath, Clinical Psychology Department, Staffordshire University; Dr Helena Priest, Staffordshire University

Documents received:

- Governance report dated 23/07/2016
- REC favourable opinion dated 24/05/2016
- SSI form ref no 191907/930563/8/120/311362/042353
- R&D form ref no 191907/930545/14/068
- Insurance Certificate 04/02/2016
- CV's / GCP certificates for research team
- Research Protocol/ Flow Chart 18/04/2016
- Patient Information Sheet v.6 – 18/04/2016
- Participant Consent form –v.1 – 25/01/2015
- Expression of Interest v.1 – 25/01/2016
- Questionnaire – Descriptive Info – v.1 – 25/01/2016

Trust web site: [www.ssthutha.uk](http://www.ssthutha.uk)

Trust Approval Letter – Version Feb 2013

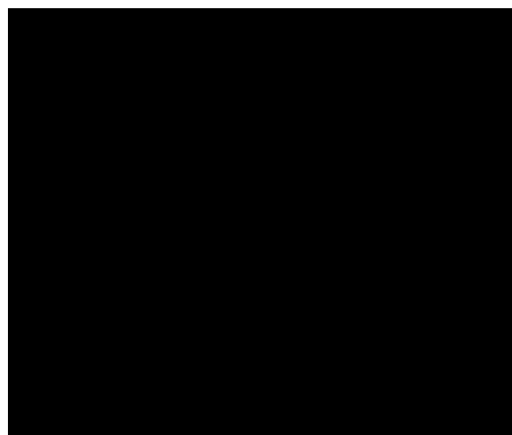


Proud To Care  
Make It Happen  
We Value Respect  
Together We Achieve

Page 2 of 3

## Appendix O2

### *Research and Development Approval from Site 2*



Wednesday, November 09, 2016

OUR R&D REF: 16/079/GHT

Katherine Williams  
Doctorate in Clinical Psychology



Dear Katherine,

Study Title:	Women's experience of unilateral breast mastectomy without reconstruction.
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Thank you for forwarding information on the above study. I can confirm the approval of [REDACTED] for this study to proceed.

Your project will now be added to our Research Register on the EDGE system including the following information:

Chief Investigator	Katherine Williams
Sponsor Organisation	Staffordshire University

This approval is issued on the basis of a review of the most recent documentation received in this office, pertaining to the REC Favourable Ethical Opinion Letter dated 24 May 2016.

DOCUMENT	Version	Date:
Research protocol or project proposal		
Participant consent form (Consent form)	1	25 January 2016
Participant information sheet (PIS) [PIS]	7	18 April 2016
Non-validated questionnaire [Descriptive information questionnaire]	1	25 January 2016
Interview schedules or topic guides for participants (interview topic guide)	1	25 January 2016
Letters of invitation to participant [Expression of Interest letter]	2	18 April 2016

If these are not the most recent documents, or there have been any amendments since, please inform the R&D Office immediately.

This Approval does not necessarily confer permission to start recruiting participants or collecting data

Where an NHS Organisation's role in the study involves the recruitment of participants to Clinical Research it is the responsibility of the Sponsor to ensure, before the start of the study, that site initiation is undertaken. Potential research participants should not be approached until site initiation has concluded and the 'green light' has been given by the Sponsor. If you are unsure whether this is the case, contact the R&D Team or the Sponsor.

It is important that all research conducted with NHS patients and/or staff complies with the Research Governance Framework. [REDACTED] We also require all studies (whether Clinical Trials of an Investigational Medicinal Product (CTIMP) or not) to be conducted to Good Clinical Conduct standards as described in the Medicines for Human Use Clinical Trials Regulations (2004).

If you are recruiting patients into any clinical study, you should have up to date GCP training within the last 3 years unless otherwise stated in the study protocol. If you do not have this, please contact the R&D Office immediately.

You must notify us at the above address, quoting our reference number if you make any changes to your study including, but not limited to, changes to the Chief or Principal Investigator, changes to end dates of studies, changes in funding, additional investigations, methodological changes or changes to the documentation. For studies that are sponsored by a [REDACTED] must be sought from the R&D Office before changes are made to any project.

Reporting requirements for Serious Adverse Events will vary depending on the study. For reporting any adverse event or reaction [REDACTED] Adverse Event Reporting and the study protocol for guidance.

You are reminded of your responsibilities under the Data Protection Act (1998) to protect the confidentiality of any identifiable data collected during the course of this research study in the same way that protection is afforded to any identifiable data collected in the course of routine healthcare activity.

Any suspicions of active fraud or misconduct must be reported to your supervisor or manager immediately and will be treated in the strictest confidence. Alternatively, such issues can be reported to an R&D Manager or directly to the Counter Fraud Office.

As part of the Research Governance Framework, during the course of your research you may be monitored to ensure that procedures in the approved protocol are being adhered to. For locally sponsored studies this will be undertaken by the R&D Office. For externally sponsored studies this is likely to be arranged by the appropriate sponsor.

The Framework also requires the dissemination of research findings to the research subjects, NHS staff and the public. For studies sponsored by [REDACTED] Trust you will be expected to produce a summary of the project and an indication of how the results from the study will be disseminated. For studies where publication of research results is not the responsibility of the local investigator, requests for such information will be made to the sponsor as required.

For locally sponsored studies, it is the Chief Investigator's responsibility to ensure all Research Ethics Committee Annual Reports and Development Safety Update Reports (for CTIMPs) are completed and submitted in a timely fashion. The R&D Office can assist in this process.

The approving Trust(s) reserve the right to terminate agreement for your research to proceed if, at any time, you are found to be in breach of the stipulations in this Approval Letter or fail to adequately meet the requirements of the Research Governance Framework, the Data Protection Act (1998) or The Medicines for Human Use Clinical Trials Regulations (2004) (where applicable).

If you need any further support or information, please do not hesitate to contact us at the above address, quoting the reference number for your study.

I wish you every success with your project

Yours sincerely,



Senior Research & Development Manager



## Appendix O3

### *Research and Development Approval from Site 3*

3 November 2016

telephone: 01283 566333

Dear Mrs Williams

Study Title	How do women experience having one breast following simple mastectomy without reconstruction? A phenomenological study.
REC Reference	16/SM/0141
IRAS project ID	191907

Thank you for your application to undertake the above research study here at [REDACTED] NHS Foundation Trust.

I am happy to confirm Trust Capacity and Capability to support the study, with which we wish you every success.

Yours sincerely



Anne Hogg  
Assistant Operational Manager (Research and Development)

## Appendix P

### *Consent Form*

Participant Identification Number for this research:

#### **CONSENT FORM**

Title of Project: **Women's experience of having one breast following mastectomy without reconstruction**

Name of Researcher: Katherine Williams

Please place your initials in the box:

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
2. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw three weeks from the date of my interview, without giving any reason. My medical care or legal rights will not be affected.
4. I consent to the researcher using anonymised quotes taken from my interview transcript.
5. I consent to take part in this study

☐☐☐☐☐

Name of Participant:

Signature:

Date:

Name of Researcher:

Signature:

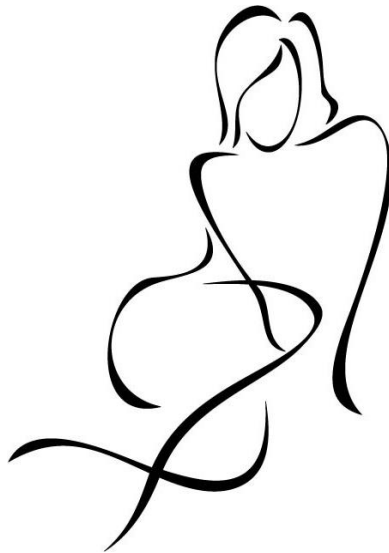
Date:

## Appendix Q

### *Expression of Interest Letter*

***Would you be willing to share your experiences of what it is like to have one breast following a mastectomy?***

---



This is a study that is interested in hearing about how women experience life with one breast. It is also interested in how women experience their remaining breast following mastectomy without reconstruction.

Participation in this study will involve meeting with a researcher and taking part in an interview lasting between 60 and 90 minutes. Depending on what is most convenient for you, the researcher can either interview you in your home or **at a location within your NHS Trust**. If you feel you could contribute to this research, then I'd really like to hear from you.

All information that you will provide will be kept confidential.

The researcher carrying out this study is a trainee Clinical Psychologist, Katherine Williams [a026521e@student.staffs.ac.uk](mailto:a026521e@student.staffs.ac.uk) who is supervised by Macmillan Consultant and Clinical Psychologist, Dr. Marilyn Owens. This research is being carried out as part of the researcher's doctoral training, in partnership with [REDACTED]

Please tick each box which applies

☐  
☐

I would like to participate in this study.

I am unsure whether I would like to participate in this study and would like a researcher to telephone me with further information.

☐

I do not wish to take part in this study

Please provide your name and telephone number so that Katherine can contact you. If you have selected the third option, please only write your name so that Katherine is aware you do not wish to be contacted further. **Please return this form in the stamped envelope provided. Thank you for your consideration.**

**Name:**

**Tel.**

## Appendix R

### ***Participant Information Sheet***

#### **Women's experience of having one breast following mastectomy without reconstruction**

### **Participant Information Sheet**

---

You are invited to take part in a research study. Before you agree to participate, it is important that you understand the purpose and nature of the study. Your decision, regardless of whether you chose to participate or not, will not affect the care you receive.

The researcher conducting this project – Katherine Williams, is a Trainee Clinical Psychologist at Staffordshire and Keele University and is employed by [REDACTED]

[REDACTED] This study is being supervised by Dr. Marilyn Owens, Macmillan Consultant Clinical Psychologist. The current study has received NHS ethical approval.

#### ***What is the purpose of this study?***

---

The purpose of this study is to gain an in-depth understanding of women's experiences of living with one breast following mastectomy. It has been identified that a large percentage of women are opting not to have reconstructive surgery following their mastectomy, yet little is understood regarding women's experience of this.

This study is also interested in how women perceive the breast that was not affected by cancer. This study hopes to gain a better insight into how women experience their remaining breast and how they manage the imbalance of having one breast. This information will help clinicians and other women undergoing mastectomy to better understand the experiences women have following mastectomy without breast reconstruction.

#### ***What will my participation involve?***

---

If you chose to participate in this study, you will be invited to attend a one-off interview with the lead researcher which will last between 60-90 minutes. The interview will comprise of questions related to a few select topics regarding your experience of living with one breast. However, the interview will be flexible, giving you the opportunity to discuss your experiences with the researcher.

The researcher can visit you in your own home to carry out the interview or on within the NHS Trust from where you have been recruited. This includes Shrewsbury and Telford NHS Trust, Gloucester NHS Foundation Trust or Burton Hospitals Foundation Trust.

It is regrettable that travel expenses will not be reimbursed. The interview will be recorded on to a Dictaphone to enable the researcher to transcribe and analyse the interview. The interview transcript will be anonymised and stored on an encrypted computer provided by the NHS. Information will be stored for no more than 10 years following the interview date.

You will be asked to **sign a consent form at the time of your interview with the researcher**. The consent form and the expression of interest form which you would have already received will be stored at Staffordshire University and will not be accessed by members outside of the immediate research team. A copy of this information and your consent form will also be stored within your patient file. This is to ensure that there is a record of the information you have been given as part of taking part in this study. This will also ensure that you will not be invited to take part in multiple studies.

### ***Do I have to take part?***

---

No. Participation is completely voluntary so you are under no obligation to take part. If you decide to participate, then you may keep this information and you will be asked to sign a consent form.

If you decide to take part, but then wish to withdraw, you can do so at any time. However, if you are interviewed by the researcher and then wish to withdraw, you can do so within **three weeks** from the date of your interview. Your interview data will be destroyed and will no longer be used within the study. You are not required to give any reasons for your wish to withdraw and **your withdrawal will not affect the care you receive**. Please contact Dr Marilyn Owens on the number given below if you wish to withdraw from the study.

### ***Who has access to my personal data?***

---

Your personal data will only be accessed by your lead breast nurse who is already involved in your care. This information is accessed in order to determine your eligibility for the study. If you chose not to take part then no further action will be required. If you chose to take part, you will be invited to return your Expression of Interest letter stating your name and contact number in order for the researcher (Katherine Williams) to contact you. Katherine will not have access to any of your personal medical information.

### ***What are the possible benefits of the study?***

---

You are unlikely to gain any direct benefit from taking part on this study. However, your involvement in this study may help other women and health professionals better understand women's experiences of having one breast following mastectomy.

### ***What are the risks of the study?***

---

This study will invite you to talk about personal and sensitive issues which you may find upsetting. In this event, the researcher will offer to take breaks and will endeavour to make you feel as comfortable as possible during the interview. Following the interview, you may also wish to speak to your lead breast nurse or the consultant psychologist involved in this research for further support.

***If you feel in any way distressed by the study after you have left then we suggest you call Macmillan Cancer on 0808 808 0000, Monday to Friday, 9am – 8pm.***

### ***What happens after the study?***

---

The findings of the study will be written up as part of a research thesis which will be submitted for publication in either an academic or professional journal.

### ***Who pays for the Study?***

---

This study forms the researcher's thesis which she is undertaking as part of her clinical psychology training. You will not be expected to pay for anything other than your travel to and from the interview site.

### ***What if I have a complaint or other concerns?***

---

If you have any questions, concerns or complaints about the study at any stage, you can contact the **Patient Advice and Liaison Service in the NHS trust from where you have been recruited:**

[REDACTED]

**Marilyn Owens** [REDACTED]

[REDACTED]

**If you decide to take part in the study, please contact the lead researcher, Katherine Williams at [REDACTED] Katherine will contact you to arrange an interview time and date that is convenient for you. You may choose to take part in this research until January 2017.**

If you wish to seek advice about taking part in research in the NHS generally, please contact our patient advice and liaison service on **0800 783 2865**

For further information, you can access the following links for information regarding breast cancer in general:

<http://www.macmillan.org.uk/information-and-support/breast-cancer/coping>

Or more specifically, information regarding changes in body image:

<http://www.macmillan.org.uk/information-and-support/breast-cancer/coping/changes-to-appearance-and-body-image/body-image-after-treatment>

## Appendix S

### ***Demographic Information Collected prior to Interviews***

Participant Number:

The following information is required as part of this study. Please circle where relevant

1. Age:

2. Marital status:

Single

In a relationship

Married

Divorced

Widowed

3. Employment status:

Full-time

Part-time

Self-employed

Currently not working

4. Time in education?

5. Do you have any children? Yes/No How many?.....

6. Who do you feel you receive support from the most? (You can circle more than one)

Family

Friends

Spouse

children

7. When did you undergo your mastectomy?

8. What stage of cancer diagnosed were you diagnosed with?

9. What treatments did you undergo before your mastectomy?

10. Were you eligible for immediate reconstruction? Yes/ No



## **Appendix T**

### ***Interview schedule***

#### **The experience of living with one breast**

- The experience of breast cancer
  - a. Can you tell me about your experience of breast cancer and mastectomy?
  - b. What was your experience of losing a breast?
- The impact this has on daily life, including relationships, friendships, work.
  - a. How has mastectomy affected your daily life?
  - b. How has mastectomy affected your relationships?
  - c. Including friendships?
- How do you experience yourself after mastectomy
  - a. How do you experience living with one breast?
  - b. How is this similar or different to how you felt before?
- Thoughts about reconstruction
  - a. What was your experience of deciding not to have reconstruction?
  - b. Were you offered reconstruction?
  - c. What information were you given about it?
- The perception of having one breast by the clinical team
  - a. How do you think your decision not to have reconstruction was understood by the clinical team?
  - b. Friends and family?
- The perception of having one breast in the context of society
  - a. How do you feel you are perceived by others after having a mastectomy?

#### **The experience of living with the unaffected, remaining breast**

- Perception of the remaining breast both before and after
  - a. How do you experience your remaining breast?
  - b. Do you have any thoughts or feelings towards your remaining breast?
  - c. How do you feel when you look in the mirror towards your opposite breast?
- The impact on daily life
  - a. How does having one breast impact on daily life?
- The experience of having mammograms on the remaining breast
  - a. How do you experience mammograms on the opposite breast?

#### **The experience of managing the imbalance of having one breast.**

- What strategies have been explored in managing the imbalance
  - a. What adjustments have you made following your mastectomy?
- Use of prostheses
  - a. Are there practical things you do to manage your breasts after mastectomy?
  - b. What are these?
  - c. Why do you use these specific ways of managing having one breast?

## Appendix U

### Examples of 'free coding'

Extract taken from Claire

10 I: um

11 P5: well obviously it was, erm it was all quite *quick*, very quick from when I found a slight lump, to

12 going to the doctors to being referred, to having the...I think when I was referred they did the

13 mammogram and everything and they sort of said that that's what they thoughts it was, then

14 obviously I had to go back, erm, yeah no, it was all very quick umm, it was all dealt with very well at

15 the erm, the place in \*\*\*\*\*

16 I: yeah

17 P5: erm they were all very friendly, *nice* erm its just it's funny, quite funny how quick it was I

18 suppose it was from like say April and then I had my mastectomy in June and it, then it was sorta all

19 over

20 I: wow yeah

21 P5: [laughs]

*Handwritten notes:*

- Society deals w cancer quickly*
- basely here*
- dealt w well*
- ambiguous diagnosis*
- cancer was all over? Surgery?*
- emotional?*

Extract taken from Louise

11 I: could you tell me about your experiences of being diagnosed with cancer?

12 P7: I was *absolutely devastated*, I'd [pause] I've always been active

13 I: um

14 P7: and I try watch what I eat, we eat good food and erm I, *I just thought it was a mistake.*

15 I: right ok

16 P7: they've made a mistake because that initial letter you get, it does state that the percentage of

17 people don't have cancer and blah-de-blah,

18 I: right

19 P7: so I thought I would be in that percentage

*Handwritten notes:*

- I tried to avoid cancer - brought into Cusker ideas at what can prevent cancer*
- Denial - Represented by not thinking he worst.*

## Appendix V

### Examples of Line by line coding

Extract taken from Petra

*Handwritten notes in orange:*  
Betrayal by body

P1: Just another thing really. Once you get the letter to go and have the mammogram obviously, and then they say they want to see you to do the biopsy then you get the letter for an appointment to see the surgeon, then you know its malignant.

I: Right ok

P1: Why would they send you to see a surgeon if they knew it wasn't malignant?

I: Yeah

P1: So when I went to see... I knew it was, I already knew it was malignant. I knew before he told me.

I: Right ok

P1: And I had already decided, erm, that I would have a mastectomy. So...

I: So even before you had met the surgeon, that, that was your plan?

P1: Yes

*Handwritten notes in red:*  
Breast cancer is no better no worse just something else to have to deal with.  
There is a process that you go through which tells you you have cancer  
I knew  
- Sense of Control one up on cancer  
I already decided

*Handwritten notes in red:*  
Control - knowing cancer

Extract taken from Phyllis

through that at 75?

I: So wha-what do you think the difference is being 75 to...?

P3: Well... I suppose if I was 30 and I wanted to go topless on a beach, I might think about it.

I: Ok

P3: But other than that I don't see the point of it and I don't see why all the expense and everything. I look no different to any other women.

I: Yeah

P3: And it doesn't make me feel less of a woman because that's a load of trollop as well that people get in their heads

I: um, so what do you think, you say that you, do you mean that your breasts aren't part of you feeling like a woman, is that what you're saying?

P3: No I'm a woman I am, whether I have a breast or not, it makes no difference, I am still a woman!

I: Yeah yeah, yes absolutely.

P3: So be quite frank with you, this one gets in the way now! [laughs]

I: Right ok, ok. So how do you feel about your, your other breast?

P3: I don't feel anything really, the one thing that has been quite funny is, when you have a wash,

*Handwritten notes in blue:*  
Identity  
I am still a woman  
→ continuity  
(wash the same)

*Handwritten notes in red:*  
why put myself through extra surgery as if it would be tolerated when you're 75?  
exposed  
Recs is expensive  
I look no different to other women  
I feel no less a woman  
People get ideas in their heads  
I am a woman with or without  
Opposite breast gets in way but I don't feel anything



Extract taken from Sue

29 P6: and I was told, that although she was very good at her job  
30 making it look reasonable.  
31 I: ok right. *looking is imp.*  
32 P6: erm  
33 I: you said the lump felt like an alien... can you tell me more about it?  
34 P6: I just felt it wasn't part of me, and it had invaded me and I  
35 to get rid of it. so, bit I was, I was scared... I've never had a general anaesthetic before, I was scared  
36 about that, I thought gosh it must really hurt, erm... but it didn't, it was fine, it really was fine, and I  
37 don't look on it as a bad experience at all. *It was*  
38 I: right, ok. So what was it like, in the kind, aftermath, you'd lost a breast, what was your experience  
39 after your treatment and having lost the breast?  
40 P6: well, it was quite funny, I came out of hospital and they had no um, what they call softies in my  
41 size, so I came out one side flat and the other side normal... and I um, I stuffed brand new Marks and  
42 Spencer's pants down my, down the left side of my bra to make it look sorta even, erm, but [pause]  
43 it wasn't, it wasn't bad, it was fine, erm I was allowed out after one day, on condition that I could  
44 manage the drain and I was determined to manage the drain that was the worst bit, having to carry  
45 this bag around with you all the time. *Feels like always a balance b/w being controlled + taking control*  
46 I: yeah *Alien - no control Can't understand it - own rules*  
47 P6: but I came out at lunchtime on Saturday and Saturday evening I did a roast chicken for  
48 everybody, dragging the bag around the kitchen. *Alien scary*  
49 I: wow  
50 P6: [laughs]  
51 I: wow ok! [laughs]  
52 P6: I was, I was just determined to carry on and, and not let it change anything and they were all  
53 prepared... my sons and my husband prepared to cook but I said no I think I'd like to do so, and  
54 they lifted it in and out of the oven for me and things like that but I just came home and got on with  
55 it. *human*  
56 I: so what was that like, your decision to just get on with it? Can you tell me more about just getting  
57 on with it?  
*Managing Control - Carer is a burden*  
*Burden*  
*Control*  
*Power by healthcare*  
*Comical*  
*Adolescent*  
*Even out at hospital it was imp to look even*  
*malemat - Sacred feminine*  
*provider*  
*protecting everyone*  
*Immediately replace*  
*So long as it looks good on the outside*  
*Imp to be able to keep managing to*  
*competence*  
*control*  
*Autonomy*  
*Strength resilience*  
*Secure in command*

## Appendix W

### *Superordinate and subordinate themes for individual transcripts*

#### **Example 1. Sue**

<b>Supordinate theme</b>	<b>Subordinate theme</b>	<b>Evidence</b>
<b>An alien invasion</b>	<b>Not a bad experience</b>	<p>I just felt it wasn't part of me, and <i>it</i> had invaded me... in the end I just wanted to get rid of it... I thought gosh it must really hurt, erm... but it didn't, it was fine, it really was fine, and I don't look on it as a bad experience at all.(34-37)</p> <p>..when I look back on it, it wasn't the <i>awful</i> thing that you think it's going to be... it wasn't that bad an experience (9)</p> <p>so, looking back it really wasn't a dreadful experience and... other people that I've met since, I've sorta said to them it's not as bad as you think it's gonna be.. (15)</p> <p>But the whole experience was not a bad one, I don't look bad and think that was a bad experience, I really don't, apart from I had to go into hospital which I didn't like, but it wasn't a bad experience (434-435)</p>
	<b>It could be worse</b>	<p>I think I was one of the lucky ones, I <i>know</i> I was one of the lucky ones (16-17)</p> <p>Most of the time, I'm not, it doesn't, well all of the time really, it doesn't bother me now, um because nobody notices, but I think.. in fact, people probably notice his eye sight more because he doesn't drive but there isn't anything <i>I can't</i> do now that I used to do before (221-223)</p> <p>I'm still quite glad that I don't have two now! [referring to having mammograms] (331)</p> <p>I know I was one of the lucky ones, that it's all gone, I didn't, I <i>never</i> had any pain (436)</p>

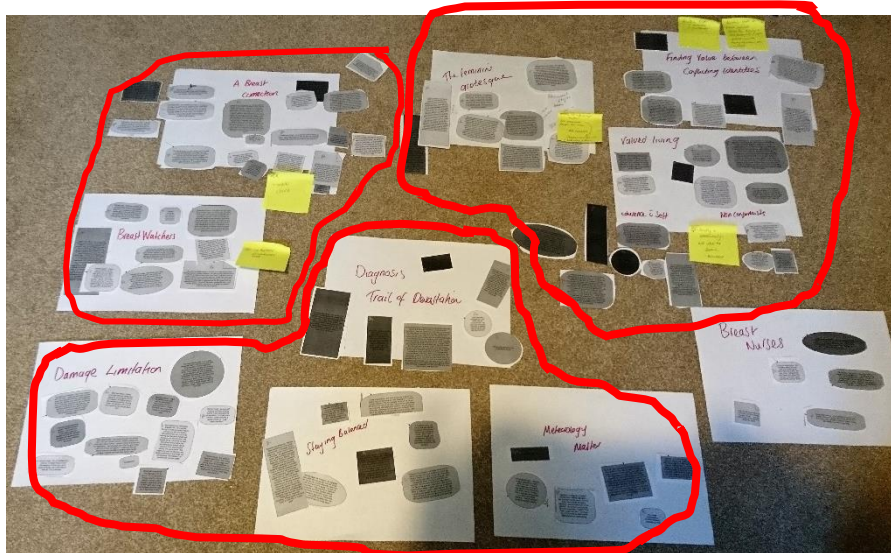
<b>Keeping up appearances</b>	<b>Defending against shame</b>	<p>...for quite a long time I felt that I'd done something wrong and then I was talking to my eldest son one day... he convinced me that I didn't have anything to be ashamed about and after that, I found I could tell people. But I did feel this really quite strong feeling of shame, I don't know why, but I just did, that I'd done something wrong, um... [pause] I know you don't sort of, can't do anything to give it to yourself or anything but rationally, I knew I hadn't but, emotionally felt that I had (203-206)</p> <p>I was ashamed to tell people and also, the other thing was I don't like people making a fuss. I don't like being made a fuss of.. I'd rather, if I'm not feeling well I'd rather be ignored (208-210).</p>
	<b>Minimise illness</b>	<p>...but I came out at lunchtime on Saturday and Saturday evening I did a roast chicken for everybody, dragging the bag around the kitchen (47-48).</p> <p>...and the funeral and everything else and, and all the time before the mastectomy I was doing things like clearing out her house and sorting things out, so I was probably concentrating more on that than (105-107)</p> <p>..In fact to be honest, we didn't really talk about it an awful lot, I <i>played</i> it down a lot, because I didn't want them to worry.. (135-136)</p>
<b>Asserting control</b>	<b>A determined maverick</b>	<p>I was just determined to carry on and, and not let it change anything and they were all prepared... my sons and my husband prepared to cook but I said "no I think I'd like to do" so, and they lifted it in and out of the oven for me and things like that but I just came home and got on with it (52-54).</p> <p>...um, but I'm not very good at following advice, I tend to do what I want to do and think well, yknow, it's my life, I'm not gonna sit here and do nothing, so... I'm quite stubborn...I'm going to do it whatever anybody says, I don't see the point...(350-351).</p>
	<b>Deciding not to reconstruct</b>	<p>...well right from the beginning, um, when um, surgeon was talking to me about various things, I decided I wasn't go to do it...(231-232).</p> <p>I can remember reading one girl who said...she also had pain where they'd taken flesh or skin or something...(241-242)</p> <p>Oh in fact had my annual check-up two weeks ago, and, I was offered it again, I won't ever say yes! I won't. The surgeon says she does it in two stages so that would be two, twice I'd have to go into hospital (255-257)</p>

	<b>Cut it off</b>	<p>Well to be honest I was just glad to get rid of it (23)</p> <p>...I thought right I'm gonna get rid of it, I'll have it off and I said to my sons I'm just gonna have it off! (84-86)</p> <p>and erm, so, it was before then I said to my sons, "I'm going to just have it cut off, you can have it cut off" I said <i>"I'm going to have it cut off"</i> and that was before I knew the options (92-93)</p>
<b>Restoring the female form</b>	<b>The breast friend</b>	<p>Its fine [the prosthesis], and I also bought myself another one for swimming...it's lighter and it's got channels behind to let the water... so I <i>keep</i> it in the swimming costume (147-150)</p> <p>I don't mind wearing it, quite happy to, it's quite comfortable yknow (183).</p> <p>[It's] sorta like a friend now...its, it's not very part of me but it's always with me. (277-279).</p>
	<b>A good seamstress</b>	<p>The surgeon was lovely, um I had a lady surgeon, she was... amazing and she was also erm, quite humorous...(10)</p> <p>And I was told, that although she was very good at her job, the surgeon would have trouble making it look reasonable (29-30).</p> <p>They gave me a whole load of painkillers and um I didn't take them because I didn't have any pain at all, I think she did a really good job (87-188)</p> <p>She did a good job of sewing me up as well, the scars quite... its disappearing now! (190).</p> <p>She must have done a really good job, she was very good at sewing anyway... she sewed me up very well (137-139).</p>

## Appendix X

### *Initial Integration of cases*

Red areas illustrate the emerging superordinate themes





## Appendix Y

### Evidence of Superordinate and Subthemes

Superordinate Themes	Subordinate Themes	Evidence	Reference (including Line numbers)
<b><i>Coping across a cancer continuum</i></b>	<b>Damage Limitation</b>	I knew it was, I already knew it was malignant. I knew before he told me....And I had already decided, erm, that I would have a mastectomy	Petra, 60-62
		No this was before theatre, this was in the anaesthetic room before I went down, the realisation that I'd had so many weeks... Holding myself together...	Petra 136-139
		...And then they gave me some about having a mastectomy and it tells you the procedure and what can happen afterwards... but at the time you...just, don't want to read it...you try and block it out but yknow, come the day when, I was, went in for the operation, I was just calm and that was it	Louise, 63-69
		I'm going to just have it cut off, you can have it cut off" I said " <i>I'm going to have it cut off</i> " and that was before I knew the options (Sue, 70)	Sue, 92-93
		I think because all along, I have been in denial somehow...about having cancer, I don't know what it is, that's all I can say, obviously I am heathy... yknow, this can't be me, this can't be happening to me	Louise, 339-344
	<b>"It Could be Worse"</b>	in fact, people probably notice his eye sight more because he doesn't drive but there isn't anything <i>I can't</i> do now that I used to do before	Sue, 222-223
		And to be honest with yer, it doesn't look too bad, I had a wonderful surgeon, and she has done a wonderful job, it's not a bad scar um, I, I thought it would have been worse...	Phyllis, 128-129
		because I think like with me, I was so lucky because it was <i>so, so</i> erm, err hadn't yknow, hadn't advanced at all, it was very early stages	Claire, 143
		so you just get, get on with this, yknow I suppose there's worse things that can happen.	Louise, 564
	<b>Mastering Mastectomy</b>	The surgeon asked me two or three times "are you sure you don't want reconstruction?" so he was quite a proponent of it	Sandra, 52-53

		oh in fact had my annual check-up two weeks ago, and, I was offered it again, I won't ever say yes! I wont. The surgeon says she does it in two stages so that would be two, twice I'd have to go into hospital.	Sue, 225-227
<b>A Breast Connection</b>	<b>A Changed Connection</b>	I was very affectionate towards them, they were my friends, but then of course y'know you get breast cancer and you realise actually that they are appendages on your body that you don't always need -and if they're going to become diseased then they need to be taken away...	Sandra, 147-149
		I did have a good old grope the other day to see if there were any lumps, but so did the doctor, so err yeah, I mean it's just an appendage now... It's weird isn't it?	Sandra, 575-574
		once I was told they had turned against me as it were [laughs]	Sandra, 105-106
		...but erm, my eldest son calls... me monoboob!... in a very very fond way	Sue, 175-177
		Oh yeah, I mean I don't take any notice now, in fact, I use it as a comedy really...Cause I can now do Mr and Mrs!	Phyllis, 120-122
	<b>A Burdensome Breast</b>	I've never been big chested, or anything, and erm I was just, I've never gone topless in the 60s/70s whatever, I've never done anything like that, and I don't know, I was just... proud of my breasts	Louise, 89-91
		Shame I didn't say "why don't you take both off" and then I needn't bother with anything.	Sue, 172
		Well actually, sometimes gets in the way more than anything else! [laughs]	Phyllis, 610
		it was quite funny to start with cause it was very smooth, I liked the fact how <i>smooth</i> it was erm and then it made it a bit odd having this one, I thought I'd rather think I'd like it smooth, <i>totally smooth</i> ... I think that was only because I just thought oh it'd just end up with one would get in the way, when I was running and stuff like that [laughs]	Claire, 175-179
		I: what's that about, getting in the way? P5: like bouncing about, ykno if I have, if I was totally flat chested, you'd be like "ooo" but no I don't think but then it wouldn't, you couldn't build up both could you? So at least now I can put something in this, this one, erm and then	

	yeah... cause I think ultimately you would want something there wouldn't you? Don't think you'd want to be totally flat chested [laughs]	
	I don't think about it [the opposite breast]... What's happened, happened, it is as it is and... I know people...they hate their remaining breast or they love their reaming breast more, you know I've heard all sorts of things...people have funny ideas	Petra, 237-238
	I suppose I do check it quite a lot. Erm, that's erm, that's one thing I do, cause then your sort of think god I've got nothing to check it against	Claire, 273
	cause I suppose when you, yknow, when you feel that one to that one, that one's different to that one but now I haven't got anything to compare it against have I?	Claire, 280-281
<b>An Inferior Replica</b>	Well it's not gonna be like a real boob is it? So you might as well have nothing... I don't know quite how they are gonna do that and it might look odd...odd-er..."	Claire, 258
	I was worried whether one would look different to the other	Louise, 111
	...smacks of... not plastic surgery, erm... y'know like having a nose job? Something that's done...to make you look better and I've never, ever considered anything like that..."	Sue, 267-272
	My recovery would have possibly been longer and it would have been more painful and uncomfortable.	Petra, 182-183
<b>Swiss Army Breast</b>	so I made my <i>own</i> swimming one I got one of these...I took all of the inside out, I got a bath sponge...put the bath sponge in and then I put it in...in my cosy, and then I swam didn't it, and then when I come out and I went in the shower, I used it as...?	Phyllis, 761-770
	but I've got to give you all these [inaudible], you've got to know if you're doing this sort of thing...you <i>need</i> to know	Phyllis, 699-702
	It wasn't too bad actually, cause, they're very sort of caring when you go back to the erm, to see the nurse and she, yknow, she gets the what she thinks is the right size for you and everything, and it felt, quite comfortable in fact	Maureen, 112-115

	when I'm wearing it now I'm not even thinking about it, 'cause I feel quite normal	
	er, I couldn't wear them, but I've just adapted and I've got very nice swimsuits, and I do yoga, so I have a breast form for yoga, I got different ones for swimming... [laughs] and er, and I've got a foam one, that initially was for swimming but I've got a better one now, which comes in very handy when I weigh-in on a Friday at Weight Watchers [laughs]	Louise, 147-151
<b>Breast Watchers</b>	I've got the main one from the hospital that I've had, well it's coming up to three years erm and then, online the Nicola jane. I don't know if you're familiar with them, they, they do swimwear and bras...yeah and I can give you some leaflets after... and I bought erm, some bras and then I brought some errr these foam prostheses for swimming.	Louise, 238-243
	you've probability never sat in a radiotherapy waiting room, everyone is in their dressing gowns and coats waiting, and I thought I just don't want to start engaging in conversations and people are telling, in quite graphic details about, I don't even know, and I just.. sit there reading my book, get in, have it done and get out again. But some people, are <i>just</i> ...it's like being a member of an exclusive club... [laughs] "I'll see you again tomorrow!" ...God!	Petra, 467-471
	yes, she did, she had her breast removed [laughs] in fact she came up here and we were talking about it and she said "oh have a look" and she just took it out and she said "catch!" and she just threw it at me!	Maureen, 536-538
	well I only got that in September so I use that erm, probably when I'm going out, I haven't at the moment I've just got the soft padded thing erm my friends mum knitted me some knitted boobs...I've got some of those [laughs] erm and in fact quite a lot at home, I don't bother to put anything in.	Claire, 118-191
	And she lives in Australia and she had err breast cancer, and she was diagnosed about a year before me and she use to post, she posted throughout her treatment and, and although I read them and erm congratulated her on her, on her blogs, and her and the information she gave, which I thought would probably be very, now I look back on and think it's probably very	Sandra, 320-328

		supportive to anybody going through the same thing... she hasn't posted for a <i>long</i> time actually but I have been in contact with her on a private level and err, just and also, I've got a friends who's, who's, went through the whole process probably a month or two before me..So you know there's a lot, just opening up those channels of communication really.	
<b>Finding Value Between Conflicting Identities</b>	<b>A Prosthetic Disguise</b>	Just I suppose you think that's normal to have two isn't it? Perhaps? [pause] But as I say, I don't always, but like I would if I was going out in an evening, I've never really thought about it why I would [laughs] it's any different to why I shouldn't bother really? But I dunno I suppose it's all part of, of when you <u>get dressed up to look yknow</u> , have them even perhaps? Hmm yeah	Claire, 458-461
		I: why wouldn't you decide not to wear it do you think?.... Louise: [laughs] I would look so peculiar.	Louise, 518-523
		Because I think then it would be then <i>obvious</i> and then I think it would draw attention to myself, I wouldn't particularly want to do that I wouldn't want people's perception of me, I wouldn't want people to feel sorry for me, I think, I think that's it...	Sandra, 187-189
		I suppose it's like people who lose an arm, or a leg, and you you just don't want to be stared at... um..my mother in law is in a wheelchair because she's old, and she said that people ignore you when you're in a wheelchair, they look above you all the time, so...	Sue, 225-227
		I think, I think I'd be... quite embarrassed if, if anyone did see that I hadn't got a breast, yes I would...because I said I don't feel like a whole person anymore, a whole woman anymore	Maureen, 139-143
		but at the time, just felt about bit, a bit conscious, yknow?...yeah, cause erm, well, you feel a bit, abnormal to start with, with yer cosy	Phyllis, 796-799
	<b>Coherent Identity</b>	I'm a woman I am, whether I have a breast or not, it makes no difference, I am <i>still</i> a woman!	Phyllis,
		I'm quite comfortable as I am I don't feel I have to conform, I am who I am and I'll do what I want basically	Petra,

	I don't feel anything really, the one thing that has been quite funny is, when you have a wash, you, you lift your breasts and wash underneath, and for a few times I was washing something that wasn't there! [laughs]	Phyllis, 47-49
	...they told me um, and I didn't quite understand and I didn't ever go and ask them but they said "don't dig the garden, always wear a glove on your left hand while washing up, always wear gardening gloves, don't Hoover..." [pause] but I didn't know whether that was just while it was healing or all the time...and in fact I ignored it all, I don't wear gardening gloves I don't wear gloves for washing up, I do Hoover and I dig the garden	Sue, 335-354
	I still feel the same as far as yknow, emotions are concerned as things like that, physically I'm not, <i>normal</i> , obviously because I've only got one breast, but emotionally and wha.. spiritually I feel, still feel the same person..	Maureen., 280-282
<b>Valued Living</b>	It is important to believe in something and God to me is somebody who is real erm, he isn't just a little.... when I did my driving exam, I had him as my passenger and things like that, yknow? He's a, he's a person in my life...he's a big influence, he's my boss...	Phyllis, 64-75
	We have such a laugh and they take the mick out of me and they're just, really nice relationship...and really, and Christmas, it's just, not expensive, we don't, I don't buy expensive but we just have a lot of fun...And they still want to come on holiday, yknow we just have a lot of fun together, good fun, they are, they are good kids...yeah, yknow what 25 and 23 would a. want to go to a Florence and Machine in concert? The year before we went to erm.... a play in Birmingham and went out for dinner and then the next day we went to the wildlife centre or whatever, the aquarium in Birmingham and then to the cinema to watch some trashy... but it was just really nice...Just the four of us being together, and they get on so well together.	Petra, 537-531
	So up until the time then my husband died 16 years ago, from then on my life seemed to change completely [laughs] so I've done some wonderful things since my husband died, sounds awful doesn't it really, I've been all around the world, two or three times, seen some amazing places, my life seemed to go	Maureen, 637-642

<i>completely</i> the other way, but I've had a lot of trauma in my life, it was <i>very very</i> hard living with my husband, I stayed with him whereas a lot of women wouldn't, but that was pretty grim...	
not really, although having, having had the same experience now as my mother and sister, my relationships with them have changed, erm, we've become closer and, and erm... I suppose [coughs] we've, we've just become closer... errr if that's possible?	Sandra, 372-374
I was more worried about not being able to do exercise [laughs]...and when I can get back on my bike again...cause obviously I got to quite a good level... starting from January from nothing... and I wanted to keep it going because I obviously then, so then, that was, that was probably the more frustrating thing	Claire, 95-100

