FACTORS INFLUENCING PATIENT CHOICE IN TYPE OF BREAST RECONSTRUCTION: A QUALITATIVE STUDY

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ABSTRACT

Background

Mastectomy involves the surgical removal of the breast, often forming part of the treatment for primary breast cancer. Current guidance recommends that all women having mastectomy should have access to choice when selecting a type of surgical breast reconstruction, unless clinically circumscribed. The National Mastectomy and Breast Reconstruction Audit found that despite this guidance there was wide geographical variation in uptake of different reconstructive options, suggesting that factors other than women's preference could have played a role. Although women's experiences of choosing whether to undergo breast reconstruction is well described in the literature, there is limited research that examines what is important to women when selecting a particular type of reconstructive surgery.

Aims

This study addresses this gap by exploring women's and clinicians' perceptions of the decision-making process taking place within the breast reconstruction consultation. It aims to answer the following research questions:

What do women with breast cancer perceive as influential when choosing a type of breast reconstruction?

What experiences were important to women with breast cancer undergoing mastectomy when choosing to have breast reconstruction?

What do clinicians think is important to women when choosing a type of breast reconstruction?

Design

A two-phase design including a qualitative evidence synthesis and a qualitative study is described in this thesis.

Methods

A search of the electronic databases MEDLINE, CINAHL, EMBASE and PsycINFO was completed using a search strategy following transparent reporting of systematic reviews and meta-analysis

(PRISMA) guidelines. Data which contributed to understanding the first research question were extracted and analysed using thematic synthesis.

Semi-structured interviews with 20 women with mastectomy and six clinicians recruited from two NHS Hospital Trusts in England were completed. Following transcription, these were analysed using descriptive thematic analysis supported by NVivo.

Results

In the evidence synthesis, four studies from the US, Netherlands and UK were included, with a total of 104 participants. Following data extraction and analysis, six themes were identified: *Appearance, Return to Normal, Natural, Perception of Reconstructive Risks, The Surgical Consultation,* and *Body Ethics*.

Analysis of interviews with women identified two themes that illustrated their decision making: *Caring for the Body* and *The Influence of the Surgeon.* Separate analysis of interviews with clinicians identified three themes: *Trust, The Clinician's Preference,* and *Clinical Restrictions on Choice.*

Conclusion

These findings provide insight into women's experiences when faced with a choice between breast reconstruction options. Women generally chose a type of reconstruction based on personal preference, perception of risk and practicality. Clinicians may need to pay greater attention to women's understanding of risk in order to truly achieve patient-centredness. This will help support women's decision-making during breast reconstruction consultations, to ensure choice is aligned with their individual needs.

CONTENTS

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GLOSSARY

ADM	Acellular Dermal Matrix
ABS	Association of Breast Surgeons
BC	Breast Cancer
BASO	British Association of Surgical Oncology
BAPRAS	British Association of Plastic Reconstructive and Aesthetic Surgeons
BMI	Body Mass Index
BR	Breast Reconstruction
BRCA	Breast Cancer Gene
CNS	Clinical Nurse Specialist
CPM	Contralateral Prophylactic Mastectomy
DIBR	Delayed-Immediate Breast Reconstruction
DIEP	Deep Inferior Epigastric Perforator Flap
DBR	Delayed Breast Reconstruction
GP	General Practitioner
IBR	Implant Based Breast Reconstruction
IR	Immediate Breast Reconstruction
LD	Latissimus Dorsi
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NMBR	National Mastectomy and Breast Reconstruction
MDT	Multidisciplinary Teams
OPBS	Oncoplastic Breast Surgeon
OPC	Oncoplastic Centre
OPU	Oncoplastic Unit
PIN	Patient Identification Number
PS	Plastic Surgeon
REC	Research Ethics Committee
R&D	Research and Development
SSM	Skin-Sparing Mastectomy
TRAM	Transverse Rectus Abdominis Myocutanous Flap

CHAPTER 1 – INTRODUCTION

1.1 Introduction

Less than 50 years ago women receiving a diagnosis of breast cancer were also hearing news of a likely premature death. If curative treatment was offered, it frequently involved surgical removal of the breast (mastectomy), usually with lymph node dissection and/or radiotherapy (Robinson, 1986). Techniques for breast reconstruction were just in their infancy (Uroskie and Colen 2004). If breast reconstruction was available, it was often delayed for months or more after the original mastectomy; there has been considerable change in practice over the last 30 years (Snyderman and Guthrie, 1971, Carlson et al, 1997, Uroskie and Colen 2004). With the introduction of the national breast cancer screening programme, advancement of surgical techniques, sentinel lymph node biopsy, and adjuvant therapies, the outcomes for women have improved. The five-year survival rate after diagnosis in the UK today is around 85% (Cancer Research UK, 2019), increased from 52.7% in the 1970s (Quaresma et al, 2015). The focus for women with breast cancer has shifted accordingly, from hoping for survival, to living with a body which has fundamentally changed.

Despite these advances, mastectomy remains an integral part of treatment for many women with breast cancer. Living with mastectomy can be difficult and complex, partly because the breast has multiple meanings. It is both a sexual and a nurturing organ, and a visible feature of womanhood that is often considered symbolic of femininity, with the breast's sexualised role contributing to the objectification of women. Irrespective of being part of the form and function of the female body, advancements in surgical techniques allow breasts to be manufactured, reconstructed, enhanced and reduced.

Today, national guidance states that women in the UK receiving a diagnosis of breast cancer that includes treatment with mastectomy should be offered breast reconstruction (Rainsbury and Willett 2012, NICE 2018). The high survival rates associated with breast cancer may also lead some women to navigate a complex landscape of cancer, femininity, sexuality and social dynamics, which is reflected in breast reconstruction decision-making. Hence, when these women face the assault of treatment, the consequent surgical intervention to rebuild is both a medical necessity and a cosmetic restoration of form and shape that may also embody personal and cultural values.

At the outset of this study, I was a junior doctor with aspirations for a career in surgery. I regularly observed and participated in consultations with women who were considering the available breast reconstruction options. These complex decision-making conversations initiated my interest in the phenomenon of decision-making, culminating in my desire to explore it further in this doctoral study.

This chapter begins with an introduction to breast cancer and breast reconstruction, including the options available to women in the UK. Following this, the National Mastectomy and Breast Reconstruction Audit will be examined, which highlighted variations in breast reconstruction uptake and satisfaction in the UK. Its findings suggested that breast reconstruction decision-making is complex and may not be fully understood. Patient-centred care and shared decision-making will be introduced, as part of the modern approach embedded into healthcare systems to best support patients to make decisions. Finally, the research questions that drove this thesis will be presented, exploring the complex phenomenon of breast reconstruction decision-making.

1.2 Breast Cancer

Breast cancer is the most common cancer in the UK, with 54,500 new cases of invasive disease reported in 2016 (Cancer Research UK, 2019). It typically occurs in women over 50 years of age and is uncommon in women under forty. In-situ breast carcinoma (a malignant precursor state of invasive breast cancer) accounts for around 6,700 new cases yearly (Cancer Research UK, 2019). The National Institute for Health and Care Excellence (NICE) recommends surgery, in the form of breast conservation surgery or mastectomy, for all women with invasive breast cancer and in-situ breast carcinoma (NICE, 2018).

Mastectomy entails excision of the breast mound as treatment or prevention for invasive breast cancer. Living with mastectomy has been associated with increased anxiety and depression, body image disturbance and reduced self-esteem, when compared with those who have had breast conservation surgery and surgical reconstruction of the breast (Al-Ghazal et al 2000, Fang et al 2013). NICE has recommended that reconstruction be made available to all women requiring mastectomy for breast cancer since 2002, however uptake of immediate reconstruction remains variable despite this (Jeevan et al, 2014). Current best practice recommends that all women who require mastectomy should have the opportunity to discuss reconstructive options. This should include explanation of both immediate and delayed surgical reconstruction, also termed 'oncoplastic' breast reconstruction, and the types of breast reconstruction that are clinically viable options (Rainsbury and Willett 2012, NICE 2018).

1.3 Oncoplastic Breast Reconstruction

Oncoplastic breast reconstruction (henceforth referred to as BR) can occur at the same time as mastectomy (immediately), or delayed following recovery from the original mastectomy. Both clinical and patient reasons can influence timing. Depending on the timing of these procedures, they are referred to as immediate reconstruction (IR) and delayed breast reconstruction (DBR), respectively. Surgical options with IR are limited to a specific mastectomy type, known as skin-sparing mastectomy. This usually, but not always, involves excision of the entire breast gland and nipple. This is usually performed via an incision around the areola, leaving a skin 'envelope' and an underlying empty pocket. It is into this space that reconstruction of the breast mound occurs. Immediate reconstruction may reap some psychological benefits, with some studies suggesting lower levels of distress and better body image/self-esteem outcomes when compared to delayed reconstruction (Al-Ghazal et al 2000, NICE 2018, Somogyi et al 2018). This may be due to preservation of the skin envelope (thought to improve symmetry with the remaining breast), whilst avoiding any distress that may accompany time spent without the breast (Al-Ghazal et al 2000, Somogyi et al 2018).

Despite the reported benefits of IR, it may not be suitable for patients with advanced disease, or those requiring radiotherapy. Also, some women may have personal reasons for preferring a delayed option. For example, women may prefer to concentrate on managing their cancer and put off further surgery until recovered, or may indeed choose to maintain the option not to undergo reconstruction (Somogyi et al 2018). In these cases, patients may be offered DBR.

Those opting not to have immediate reconstruction are normally offered an ‘external prosthetic’ device. This is an artificial breast-shaped form that fits into a bra, thereby recreating the natural contours of the breast through clothing. Women’s experiences of wearing the external prosthetic are mixed (Gallagher et al 2009, Glaus and Carlson 2009). The weight, durability, texture and style of the prosthetic can present challenges; and some women experience poor availability of mastectomy bras, with limited styles, colours, and affordability (Gallagher et al 2009). A poor experience with an external prosthesis has been a cited as a motivating factor to choose breast reconstruction (Begum et al 2011, Harcourt and Rumsey, 2001, 2004, Reaby 1998, Somogyi et al 2015)

1.3.1 Types of Oncoplastic Breast Reconstruction

Women who opt for reconstruction generally can choose between two types of breast reconstruction. These include implant-based or tissue expander reconstructions, where a prosthetic is placed internally to reconstruct the breast mound, or an autologous flap reconstruction, where the patient’s own tissue is used to reconstruct the breast mound).

1.3.1.1 Implant-Based Reconstruction

Implant-based or tissue expander breast reconstruction will collectively be referred to henceforth as IBR. Implants for surgical breast reconstruction were first developed in the 1960s (Serletti 2006), and IBR remains the most commonly performed type of reconstruction in the United Kingdom (UK) and the United States (USA) (Albornoz et al 2013, Jeevan et al 2014). Tissue expanders are often used instead of fixed-volume breast implants, as they can be sequentially expanded in small pockets of skin (ie once the breast gland is removed during mastectomy), stretching both the expander and the surrounding pocket of skin. Once the skin pocket or envelope has enough space, a fixed-volume implant can be inserted.

Comparative advantages with respect to autologous reconstructions include shorter procedure duration, fewer complications, fewer scars, quicker recovery and lack of donor site morbidity (Somogyi et al 2018). The ideal candidate may lack significant excess tissue required for autologous reconstruction, and therefore tends to be of average to slim build (Somogyi et al 2018). IBR is generally not recommended in delayed breast reconstruction in the context of post-mastectomy radiotherapy. This is due to irradiation causing diminished skin quality with reduced elasticity and blood supply. Implant-only reconstruction in this context would carry increased risk of wound breakdown and implant extrusion, with cosmetic results thought to be poorer in delayed IBR, following radiotherapy (Jeevan et al, 2014). Autologous reconstruction is better suited to delayed reconstruction as irradiated skin can be replaced along with the breast mound.

Complications of IBR include capsular contracture (immune-mediated 'scarring' around the implant, which can cause hardness or 'lumpiness'), rupture of the implant, visible implant deformity, malposition, and in some cases, a less natural appearance or feel (Somogyi et al 2018). In the long term, they may require exchange, for example if there is clinically significant rupture, capsular contracture or malrotation. Generally, modern breast implants do not require routine replacement (Rainsbury and Willett, 2012). Unfortunately, historical scares and recall of substandard products, such as the UK withdrawal of the French Poly Implant Protheses (PIP) implant in 2010, and the FDA withdrawal of silicone gel implants in the United States in 1992 (Palley, 1995, National Health Service, 2019), have impacted on public perceptions of implant safety.

1.3.1.2 Autologous Reconstruction

Autologous flap BR involves reconstruction of the breast mound using the patient's own tissue. The donor tissue can be taken from a variety of sites, including muscle of the back (latissimus dorsi), abdominal fat (with or without muscle), thigh or gluteal muscle. The most commonly performed autologous reconstructions in the UK utilise the latissimus dorsi muscle or abdominal tissue as the donor site (Mennie et al 2017). The tissue can either be in close proximity to the breast, and therefore connected to its original blood supply (a pedicled flap), or it can be removed from its original blood supply and reconnected to a new vessel near the breast (a free flap). A free flap uses technically demanding microvascular techniques to reconnect the tissue to a blood vessel. These techniques are primarily performed by specialised plastic surgeons, as they require specific training. In comparison to IBR, the advantages of the autologous technique include a natural appearance that can accommodate changes in body weight, and fewer procedures in the long-term (Somogyi et al 2018). Complications include partial or complete failure of the flap, as well as infection, wound dehiscence, hernia and weakness around the donor site. These procedures take longer to perform, have a longer recovery period, and pose increased risk of short-term complication. Ideal candidates are typically not obese, have few co-morbidities (if at all), and need adequate tissue at the donor site (Somogyi et al 2018). Compared to pedicled flaps, free flaps carry increased risk of flap failure due to the initial division from their native blood supply, and frequently patients experience a longer recovery and operative procedure (Somogyi et al 2018).

Autologous reconstructions using abdominal tissue include the Transverse Rectus Abdominis Myocutaneous (TRAM) flap reconstruction and the Deep Inferior Epigastric Perforator (DIEP) flap reconstruction. They differ in that the TRAM sacrifices some of the underlying rectus abdominis muscles, which can cause donor site morbidity, such as abdominal bulge or hernia. TRAMs are also usually performed using a pedicle, thereby retaining its connection to its initial blood vessel, whereas the DIEP is a free flap. The DIEP is the most commonly performed free flap in the UK (Mennie et al 2017). As the DIEP does not damage the underlying muscle, and large amounts of tissue can be harvested through abdominoplasty (often colloquially termed a “tummy tuck”), it is widely regarded as the gold standard reconstruction (Khajuria et al 2017).

The most commonly performed pedicled flap in the UK is the Latissimus Dorsi (LD) myocutaneous flap (Mennie et al 2017). The muscle is tunnelled through the axilla to recreate the breast mound, whilst still connected to its own blood supply, and therefore can be viewed as safer than DIEP due to a lower risk of flap loss (Somogyi et al 2018). Due to the size of the muscle, it generally provides a smaller reconstruction than the DIEP, and is therefore typically utilised in patients with minimal abdominal tissue or previous scarring after abdominal surgery (Somogyi et al 2018). For women with larger breasts, an implant can be added underneath (implant-assisted LD). Due to loss of supporting musculature, this reconstruction can lead to decreased range of movement and strength of the surrounding area, in particular the ipsilateral arm (Blackburn et al 2018). As with any autologous flap, there is risk of donor site morbidity, such as seroma (build-up of serous fluid, (Sajid et al 2011), haematoma, wound dehiscence, and infection.

1.3.2 Delayed-Immediate Breast Reconstruction

The delayed-immediate technique can be employed for women who will likely require radiotherapy but want the benefits of IR (Kronowitz and Kuerer, 2006). It is not always known if radiotherapy will be required in advance, or at the time of initial surgery, therefore it is not uncommon for decisions about adjuvant treatment to be made after histological analysis of the mastectomy specimen. When there is a possibility of radiotherapy, this technique allows immediate reconstruction with a tissue expander, which preserves the skin envelope. During radiotherapy the tissue expander can be deflated, allowing effective irradiation, and then re-expanded once treatment is completed. At a later date, a definitive reconstruction can occur, with exchange of the expander for either an implant or an autologous flap (Kronowitz and Kuerer, 2006), however the initial tissue expander doesn’t necessarily require removal. It is often termed the IDEAL technique (Immediate-DElayed AutoLogous Breast reconstruction) when the temporary reconstruction is followed by an autologous flap (Fertsch et al, 2017) Preservation of the skin envelope used with this technique can bring the cosmetic benefits of IR whilst still ensuring satisfactory oncological treatment.

1.4 Breast Reconstruction in the United Kingdom

Surgical decision-making in breast reconstruction is complex, involving a choice between several distinct procedures, some of which are extensive and invasive. Hence, women are required to be engaged in the decision-making process and manage a large amount of information, including risks and benefits. There are also numerous clinical criteria that can impact and/or limit a patient’s preference. These include the patient’s general health and wellbeing, and cancer staging (or severity) and treatment, which are considered by surgeons and other professionals within the multi-disciplinary team. Given this complexity, it is unsurprising the National Mastectomy and Breast Reconstruction Audit identified variations in care, and the data obtained led to the development of new national guidance aimed at standardising practice (see section 1.4.3 below). The audit was a unique and unprecedented endeavour, given the number of women, clinicians and hospitals involved. Before the national audit is discussed however, context must be provided by way of a brief introduction to the role of the reconstructive surgeon and the UK breast reconstruction referral pathway.

1.4.1 The Reconstructive Surgeon

The breast reconstruction service in the UK is delivered by surgeons of two different surgical backgrounds, oncoplastic breast surgeons (OPBS) and plastic surgeons (PS). Breast surgeons, who are trained as general surgeons, can complete subspecialisation training in oncoplastic breast reconstruction after specialising in breast cancer surgery. This type of reconstructive surgeon is referred to as an oncoplastic breast surgeon, and they usually perform IBR and sometimes LD reconstructions, as well as the initial mastectomy. Not all breast surgeons undertake this subspecialisation, therefore they perform mastectomy but not reconstruction. Plastic surgeons have a different training programme. Those who specialise in breast reconstruction are adept in general reconstructive techniques as well as microsurgery. This allows them to perform all major types of breast reconstruction, but they do not usually perform the initial mastectomy or treat breast cancer itself.

Therefore, the initial mastectomy must be done by either a breast surgeon or oncoplastic breast surgeon, but referral to a plastic surgeon is necessary if the patient wishes to discuss, and be considered for, a free flap reconstruction. For an immediate DIEP flap reconstruction, both a breast cancer surgeon and a plastic surgeon will be involved. For immediate IBR and LD flap reconstructions, both could be managed independently by an OPBS (depending on their procedural repertoire), or by a breast surgeon with a plastic surgeon. Delayed reconstruction would solely require the appropriate reconstructive surgeon. Unfortunately, fewer plastic surgeons are trained in the UK, limiting availability to specialist centres and/or larger cities. Women living in some parts of the country, particularly rural and remote communities, may have to travel and see a new surgeon for their desired procedure.

The organisation of breast reconstruction services can be described as a ‘hub and spoke’ model (Potter et al, 2013), in which centres for plastic surgery form the ‘hub’ and smaller centres with OPBSs form the ‘spokes’. The configuration of these types of centres were explicated in national guidance: ‘*Oncoplastic Breast Reconstruction: Guidelines for Best Practice’* (Rainsbury and Willett, 2012 - the rest of the guidance will be introduced in section 1.5). Rainsbury and Willett (2012) described the ‘spoke’ as an oncoplastic unit (OPU), which should serve a population of about 250,000 or more, and have a lead OPBS (sometimes supported by a reconstructive plastic surgeon). The OPU should perform 25 or more major oncoplastic procedures per year, including primary reconstructions of IBR and LD flaps, but not free flaps. The ‘hub’ was described as an oncoplastic centre (OPC), a major reconstruction centre which typically serves a large region, and has the expertise to manage tertiary referrals. The OPC should be comprised of a lead surgeon with at least three other surgeons, two of whom should be able to perform microvascular, free-flap procedures. *All* reconstructions should be performed by the OPC, including a range of pedicle and free flaps, and the OPC should perform over 100 major procedures per year. OPUs must have an established referral pathway to an OPC, so that all clinically suitable women have access to free flap reconstruction. All women requiring BR should be discussed in a specific oncoplastic multidisciplinary meeting which should include a plastic surgeon, although a recent report suggests that this target is far from being met (MacNeill and Irvine, 2021).

1.4.2 The UK Breast Reconstruction Referral Pathway

Once a woman suitable for immediate reconstruction is offered a mastectomy, the clock starts to ensure the performance targets for cancer referral are met by the healthcare provider. Women should be offered a date for operation within 31 days – the ’31-day decision to treatment target’ (Jeevan et al, 2014, Rainsbury and Willett 2012; p11). The implications of these guidelines are significant. If a woman is suitable for BR and chooses reconstruction, she must be referred to a reconstructive service (some hospitals do not have an OPU), seen by a reconstructive surgeon, decide upon a reconstructive modality, and then a suitable theatre slot for the surgeon(s) has to be identified - all within the 31-day window. In OPCs, this may not be an issue, as both OPBSs and PSs will likely be available. In order to meet the '31-day decision to treatment' target to specialist reconstructive services with a different provider, referral will be required and delays may result in target breaches. Delayed reconstruction imply a past mastectomy, hence referrals are not subject to such time sensitive cancer performance targets. There is consequently no maximum time after mastectomy that precludes referral for DBR.

1.4.3 The National Mastectomy and Breast Reconstruction Audit

As outlined above, the National Mastectomy and Breast Reconstruction (NMBR) Audit was commissioned in 2006 to describe the provision of mastectomy and breast reconstruction services in the UK. Designed by the Clinical Effectiveness Unit at The Royal College of Surgeons of England, it was the largest prospective audit of breast reconstruction ever carried out (Cutress et al 2013). The audit was undertaken as a joint venture by professionals of the Association of Breast Surgeons (ABS, of BASO – The Association for Cancer Surgery), the British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS), the Clinical Effectiveness Unit of the Royal College of Surgeons of England, the Royal College of Nursing and the NHS Information Centre for Health and Social Care. It involved collection of both operative and patient reported outcome data, and has not been repeated since 2006.

There was extensive participation, as 150 English NHS Trusts, six non-English Trusts (5 Welsh and 1 Scottish) and 114 independent hospitals took part. During the study period of 1 January 2008 and 31 March 2009, data were collected prospectively from units that provided mastectomy and breast reconstruction services. Patient and clinician reported data were collected for women aged 16 and over with a diagnosis of breast cancer or DCIS, who underwent unilateral mastectomy or breast reconstruction. Clinician reported data included information on the type of operation performed and patient demographics, as well as procedural complications, whereas patient reported outcomes were collected via the BREAST-Q questionnaire, at three and eighteen months post-procedure. The BREAST-Q is a health-related quality of life and patient satisfaction questionnaire, developed for outcome monitoring and comparison between different reconstructive and cosmetic breast surgical techniques (Pusic et al, 2009). Four scales of the BREAST-Q were utilised to compare mastectomy to IR and DBR (both IR and DBR subdivided by reconstructive modality): *Satisfaction with breast area appearance*, *Emotional wellbeing*, *Physical wellbeing*, *and Sexual wellbeing* (Jeevan et al 2014).

1.4.4 National Mastectomy and Breast Reconstruction (NMBR) Audit Results

Results of the audit were published in the *Journal of Plastic, Reconstructive and Aesthetic Surgery* (Jeevan et al, 2014). In the period of 1 January 2008 to 31 March 2009, complete operative data was submitted for 18,216 women, which was estimated to be 81.4% of those eligible at the involved NHS English Trusts. As over 80% of eligible women were involved, the findings provided unique benchmarking information about national provision of clinical care and patient reported outcomes. Of the 18,216 women for whom complete operative data were submitted, 16,485 had a mastectomy, of which 3389 (20.6%) had immediate reconstruction. The 1731 remaining women opted for delayed breast reconstruction after previous mastectomy. In total, 6882 women (37.8%) returned the three-month patient reported outcomes questionnaire, and 7110 (39.0%) returned the 18-month questionnaire.

The most commonly chosen immediate reconstruction was implant-based or tissue expander, with 1246 (36.8%) women opting for this, followed by pedicled autologous flaps (932/ 27.5%). The most commonly chosen delayed reconstruction was the free flap, chosen by 566 women (32.7%), followed by similar numbers for pedicled flaps (446/25.8%) and pedicled flaps with implant/expander (438/25.3%). Few women had delayed IBR, most likely due to post mastectomy radiotherapy reducing skin quality, as described in section 1.3.1.1.

Variation in availability of choice across cancer networks was apparent, for example in two of the three networks with the highest rates of immediate reconstruction, free flaps represented almost half of all procedures. In the third network, over 70% of immediate reconstructions involved pedicled flaps, with no free flap procedures performed. Also striking was the significant variation in the uptake of immediate reconstruction across cancer networks, which ranged from 9-43%. This was not explained after accounting for age, patient comorbidity and tumour profile.

Patient reported outcome measures relating to information provision identified that about 90% of women felt they had received the right amount of pre-operative information about their chosen procedure (mastectomy, IBR or DBR). Of the women who underwent mastectomy only (with no reconstruction), only 49.6% were 'very satisfied' with the amount of information received concerning reconstructive options, compared to 64.6% and 73.0% for IR and DBR respectively. Satisfaction with the appearance of the breast and wellbeing varied, but was generally higher with autologous than implant-only reconstruction, for both IR and DBR. Implant-based reconstruction yielded the lowest scores on the scales of *breast area appearance, emotional wellbeing* and *sexual wellbeing* of all reconstructions, both immediate and delayed. . Notably, immediate implant-based reconstruction yielded similar results across the same three scales as women who chose to have mastectomy only.

Women who had delayed reconstruction generally reported higher scores on the BREAST-Q. Jeevan et al (2014) suggest various factors that could account for this, suggesting caution when comparing quality of life figure between the mastectomy, IR and DBR groups. First, those with immediate reconstruction only compare their reconstructed breast to their breast prior to mastectomy, whereas those with delayed reconstruction compare their reconstructed breast to being without a breast. Second, those women who chose immediate reconstruction typically received adjuvant therapy which may have negatively influenced satisfaction with their recovery. Those who underwent delayed reconstruction were more likely to have completed adjuvant treatments (if required), sometime before the study, and therefore may have had an overall more positive experience. Lastly, those with delayed reconstruction may have experienced a 'response shift', where their views or expectations changed over time, whereas those undergoing immediate reconstruction had lived with the breast cancer diagnosis for a shorter time.

These results sparked my interest in breast reconstruction decision-making and led to the development of this research study. The significant variation in uptake of immediate reconstruction could be accounted for by clinical factors, such as regional variation in thresholds for adjuvant therapy, or women opting for delayed reconstruction at a future date (Jeevan et al, 2014). Other possibilities should be considered, including the way in which options were presented or communicated by the surgeon may have contributed to variations. The significant proportion of delayed free flaps undertaken compared to immediate, and absence of immediate free flap reconstructions reported in one cancer network, suggest that access to plastic surgery may be a limiting factor to choice in some areas in the UK (Jeevan et al, 2014). Interestingly, the most frequently chosen form of immediate reconstruction, IBR, generated some of the lowest BREAST-Q scores across reconstructions, with results comparable to women who had mastectomy only.

The authors state that comparing BREAST-Q scores between procedures should be done with caution, but nonetheless it is intriguing that the procedure most commonly undertaken appeared to be the one with lowest satisfaction figures - similar to having mastectomy only. Although the delayed-immediate approach could contribute to the rate of immediate implant-based reconstruction, nonetheless the levels of satisfaction raised concern. Typically, "*regret and dissatisfaction with outcome are associated with poor or inadequate information provision that does not meet a patient's individual needs*" (Rainsbury and Willet, 2012, p15), yet according to the audit findings, 90% of women felt that information provision was 'good'. These findings raise questions regarding the content and delivery of information in the surgical consultation. They also suggest that perhaps clinicians do not completely understand why women choose to have implant-based reconstruction.

The NMBR Audit identified that decision-making may be more complex than previously thought. In addition to the specific procedural risks and benefits, and a (possibly recent) diagnosis of cancer, it became clear that women choosing breast reconstruction also had to contend with logistical issues associated with access to plastic surgeons and national cancer targets. Additionally, there were possible communication biases within the surgical consultation itself, and/or clinicians that did not fully understand what was important to women who choose to have implant-based reconstruction.

1.5 Decision-Making in Breast Reconstruction

The results of the NMBR Audit were a driver for the development of a national breast reconstruction guideline – *Oncoplastic Breast Reconstruction: Guidelines for Best Practice* (Rainsbury and Willett, 2012). This guidance, developed in 2012, involved a number of organisations, including ABS and BAPRAS. It described a set of 25 quality criteria against which best practice standards could be monitored and compared. Many of these standards sought to address the variations in care evidenced in the NMBR Audit, including levels of pre-operative information provision, and access to services and outcomes both clinical and patient-reported.

The *Oncoplastic Breast Reconstruction: Guidelines for Best Practice* (Rainsbury and Willett, 2012) recommended that all women for whom mastectomy is planned should have both immediate and delayed breast reconstruction discussed, and should be offered a choice where appropriate (barring those with significant contraindications). Second, all relevant breast reconstruction options should be discussed with *equal* weighting, regardless of local availability. Lastly, all women should have their psychological wellbeing screened and assessed preoperatively. This entails review by a suitably trained member of the MDT, which can include a clinical nurse specialist. The guidance suggests assessment for potential psychological distress, recognising the impact of cancer on women's daily lives, mood, relationships and work. The assessment should involve delivery of psychological techniques such as 'problem solving' (p61), to help manage psychological symptoms. Those with more complex psychological requirements should according to the guidance be referred to more specialised services, including counselling by an accredited practitioner or mental health services.

The recommendations recognise that choice of reconstruction is dependent upon many factors, including: *"Occupation, activities and lifestyle."* (p13); *"Patients' expectations, choice, goals and attitude to risk*." (p13); and *"Likely impact of recovery time on family, employment and daily activities."* (p13). The guidance further recommended that standardised information sources detailing procedural risks and benefits should be provided (p11). The patient's preferences for information and involvement in the decision-making process should also be sought and clinicians should avoid emotive or persuasive language when discussing possible choices.

Important aspects of information provision identified by the guidance included explicit mention that the reconstructed breast will not look and feel the same as a natural breast (p15). Also discussion of psychosocial implications of BR, in particular that it may take one year or more to adjust to the reconstructed breast and altered body image (p15). During the decision-making process and treatment, women should have access to psychosocial support as well as a breast care nurse with expert knowledge of BR (p16, p 18). Those who are having difficulty making a decision should be identified and referred for support (p18). When considering BR, women should be able to access a variety of resources for information and support, which include the opportunity to learn from the experiences of women who have had similar reconstructive procedures (p16).

Overall, the guideline sought to standardise the process of information provision by including discussion of all types of reconstruction, possible outcomes, and assessment of patient's preferences for involvement in decision-making. Although the clinician's recommendation of procedure should accommodate individual factors and choice, there was little detail provided about *how* to elicit the patient's preference. This omission in the guideline seems significant given descriptions that suggest an individualised approach, particularly as the NMBR Audit findings suggest that some clinicians may not understand why women choose particular reconstructions.

1.5.1 Patient Preference

Identifying patients' preferences in consultations is widely acknowledged to be difficult across many areas of medicine. In their report for the King's Fund, Mulley et al (2012), argued that doctors frequently were unable to accurately elicit patients' treatment goals or priorities. This failure was termed a silent 'misdiagnosis' by the authors, and they suggested that clinicians view disease or illness identification as more important than identifying the patient preference. They presented three arguments. Firstly, they explained that patients make different choices when well they are well informed. This suggests that the manner in which clinicians present surgical decision-making may not identify the patient's actual preference. This is supported in findings from Stacey et al's Cochrane review (2017), regarding the use of decision aids for people facing health treatment decisions. They found the amount of patients choosing major elective invasive surgery decreased in favour of more conservative options when decision aids were used.

Secondly, Mulley et al argued that doctors may not fully comprehend the outcomes that patients prioritise. This was predicated on Lee et al's (2010) study, where healthcare providers and patients were provided with a set of 'candidate facts and goals' in patient-friendly phrasing, including good and bad health choices/outcomes in breast cancer and breast reconstruction. Healthcare providers and patients selected what they perceived to be the most important statements and Lee et al found significant differences. Firstly, healthcare providers believed that 71% of women would have viewed keeping their breast as a top priority in breast cancer; however only 7% of patients agreed. Secondly, healthcare providers believed that 96% of women undergoing chemotherapy would have ranked living as long as possible as a top priority; although only 59% of women reported this. Thirdly, no healthcare providers thought that women saw avoiding the need for an external prosthetic as important when considering breast reconstruction; 35% of women disagreed.

Although these examples of doctor 'misdiagnosis' were based on findings from an American population, Mulley et al's third argument is relevant considering the NMBR Audit findings. They suggested that wide variations in care between geographic areas are likely to have multiple plausible contributing factors, including: i) variations in the delivery of models of care that are known to be effective, ii) variations created by doctors with different opinions on treatment when no option is clearly the best, iii) accurate diagnosis of preference, iv) preference misdiagnosis and v) variations in aggregate health states. The authors suggested that in the UK these variations were likely to be small in factors (i), (iii) and (v). So if total variation is viewed as the sum of these causes, then it is more likely that the largest variation is accounted for by doctors holding different opinions about 'best' treatment and misinterpretation of patient preference.

Based on these arguments (Mulley et al, 2012) there may well be a degree of 'misdiagnosis' of patient preference in breast reconstruction services in the UK, particularly in respect to selection of type of reconstruction. A patient-centred approach to healthcare might improve identification of the patient preference as it represents a progression from the traditional, paternalistic type of doctor-patient relationship to one that prioritises, encourages and values patient preference (Delaney 2018). Modern health services, if committed to delivering quality healthcare, should value the ideals of patient-centred care (Kitson et al 2012, Langberg et al 2019).

1.5.2 Patient-Centred Care

The concept of patient-centred care was introduced by Enid Balint in 1969 in relation to general practice. It was heralded as an approach that could reap benefits compared to traditional illness-centred medicine (IOM, 2001). Based on Michael Balint's work, she suggested that some patients would be better served by an examination of the whole person when making a diagnosis, as opposed to the discovery of localised illness (Balint, 1969); she argued "*… the patient, in fact, has to be understood as a unique human-being.*" (p269).

Over the course of the next 50 years, patient-centred care has evolved from an idea to a core dimension of what many consider to be high quality healthcare. Indeed, many national health systems (ie the United States, Australia and the NHS), the World Health Organisation (WHO), and health policy organisations such as the King's Fund (Kitson et al 2012, Langberg et al 2019) recognise the primacy of patient-centredness. Despite this there is no universal definition in the literature, it remains somewhat conceptually vague, and often appears as a catchphrase used by managers and/or politicians to appear to be on the patient's side (Davies 2007, Kitson et al 2012, Langberg et al 2019).

Gerteis et al (1993) were one of the first groups to attempt to define patient-centred care and its attributes. This work was adopted by the Institute of Medicine (IOM), now the National Academy of Medicine, a non-profit non-governmental US organisation that advises on national and international issues including health, medicine and health policy. The IOM advised that health systems should provide patient-centred care as a core indicator of quality (Kitson et al 2012). Subsequently Stewart et al (1995), suggested a set of six interactive, patient-centred communication components that later were shown to improve outcomes, one of which was efficiency of care (Stewart et al, 2000). These were built upon by Mead and Bower (2000) in their review of the key dimensions of 'patient-centredness'. They offer a five-dimension model:

i) *The biopsychosocial perspective* – encouraging a broader sense of understanding of the patient, not just the biomedical factors but also social and psychological elements.

ii) *The 'patient-as-person'* – advocating an understanding of the patient's individual experience of illness, understanding the personal story and meaning behind illness.

iii) *Sharing power and responsibility* – promoting an ideal of an equal doctor-patient relationship, moving away from the conventional paternalistic model, in which patients deferred to medical authority.

iv) *The therapeutic alliance* – affording increased priority to the relationship between the doctor and the patient. It involves an agreement of treatment goals, ensuring that the patient understands the relevance of treatment options and that the patient perceives the doctor as sympathetic, sensitive and caring.

v) *The 'doctor-as-person'* – self-awareness of doctors, realising their own emotional response to the relationship with the patient, recognising that the doctor and the patient cannot be viewed as separate, and will influence each other.

Since then two major reviews of patient-centred care (Kitson et al, 2012, Langberg et al, 2019) have been published, which show similarities with earlier work but consolidated patient-centredness to two core concepts. These include understanding the patient as an individual (Mead and Bower's dimensions i and ii), and secondly, the doctor-patient relationship (dimensions iii and iv). The 'doctor-as-person' dimension (v) has not received as much attention. However, both introduced a contextual element as a third core concept into their definition of patient-centred care - '*the coherence of treatment in the healthcare system*' (Langberg et al 2019, p 1234), or '*the context where the care is delivered*' (Kitson et al, 2012 p 11). Langberg et al concentrate on co-ordinated care/ preventing loss of continuity, whilst Kitson et al's third concept focuses on systems issues, such as access to care, a therapeutic environment and supportive organisational system. Regardless, these models equate patient-centred care with quality of healthcare.

1.5.3 Shared Decision-Making

Shared decision-making is a central tenet of patient-centred care (Barry and Edgman-Levitan, 2012). If shared decision-making (SDM) is at the heart of patient-centred care, then S*haring power and responsibility* and creating *The therapeutic alliance*, as described by Mead and Bower (2000), should form part of the doctor-patient relationship. SDM represents a middle ground in decision-making, between a paternalistic approach led by the doctor and informed choice driven by the patient (Makoul and Clayman, 2005). Charles et al (1997) first described SDM as: i) a process involving the clinician and patient; ii) both participating in the decision-making process; iii) information sharing is a pre-requisite; and iv) both parties agree on a treatment decision. More recently, Makoul and Clayman (2005) reviewed this model and proposed that a shared decision must include:

- Firstly, a discussion between patients and providers must define and/or explain the problem that needs to be addressed
- Then, the physician should present the options for treatment, and patients should also raise options of which they may be aware
- This is followed by a discussion of pros and cons of these options with regard to different perspectives on the relative importance of benefits, risks and costs; these become evident through patients explaining their values and preferences and physicians sharing their knowledge
- Finally, a discussion of viability of options including patients' ability to follow through with a plan
- Throughout this process, both parties should periodically check understanding of facts and perspectives, providing further clarification as needed

SDM has become central to patient-centred care, but is also now viewed as an ethical imperative in modern healthcare practice (Elwyn et al 2013). There are consequently multiple 'how to' models for application in clinical practice (Coulter and Collins 2011, Elwyn et al 2012), yet the evidence that SDM is widely utilised in everyday practice is less clear (Coulter and Collins 2011). Legare et al's 2008 systematic review identified barriers to SDM voiced by clinicians (for example, clinicians felt that patients did not want SDM). A subsequent review identified that patients *wanted* to be involved in their healthcare decisions, particularly in cancer (Chewning et al, 2012). This has also been reported earlier in the breast cancer literature (Bruera et al 2002, Janz et al 2004), so reasonable to assume that this would also apply to breast reconstruction.

1.6 Development of Clinical Practice in Breast Reconstruction

Breast reconstruction is an innovative, fast-moving field. The writing of this thesis began in 2015, and from then to the present date there has been much development in clinical practice. Most relevant is the change in the usage of LD flap reconstruction, from which surgeons have moved away due to more advanced IBR techniques (Kankam et al, 2017, Mennie et al 2017, Kokosis et al 2019, Jeevan 2020, Wignarajah et al 2020). This has been attributed to the introduction of acellular dermal matrices (ADMs) (Wignarajah et al 2020), which are soft tissue substitutes that can be utilised in conjunction with IBR (Kankam et al, 2017). Since introducing IBR with ADMs in 2013, one major UK OPC reported reducing LDs from about one third of reconstructions to about one tenth (Kankam et al, 2017). Compared to the LD flap, implant reconstructions with ADM are faster and less technically demanding (Wignarajah et al 2020), and consequently, LD reconstructions are now often viewed as a salvage procedure (for example, to be used if another reconstruction were to fail) (Kokosis et al, 2019). Between 2006 and 2013, IBR has increased to over half of immediate reconstructions in the UK, and DIEPs to about 42% of delayed reconstructions (Mennie et al, 2017), highlighting the increasing trend towards IBR and DIEPs as the most commonly performed procedures.

Despite technical advancements, offer of immediate breast reconstruction still varies geographically in the UK (Jeevan 2020). It has been suggested that possible conscious or unconscious 'bias' (Jeevan 2020; p112) among clinicians has contributed to this variation in offer of immediate reconstruction; and the UK is outperformed by the USA, in terms of rates of immediate reconstruction (Wignarajah et al 2020). Variation in care has precipitated the development of the Getting it Right First Time (GIRFT) national programme, which aims to improve access to services of varying specialties, and reduce unwarranted variation. In a recent GIRFT report, MacNeill and Irvine (2021) have identified significant variation in practice linked to the availability of plastic surgeons performing free flaps in hospital trusts, with about one third of women receiving a free flap where all types of reconstructions are available, to less than one fifth where all types are not available. They describe other contributing factors, which can include the ’31-day target’ and backlogs in tertiary services in certain geographic areas causing restriction of referrals (MacNeill and Irvine 2021). Variations in restrictions by local clinical commissioning groups (CCGs) also impact the amount of procedures that women can receive (MacNeill and Irvine 2021). Another current issue affecting women is lack of access to free-flap reconstruction during the Covid-19 pandemic; reconstructive surgeons have recently described how to safely reintroduce free-flap reconstruction in the Covid era (Masud et al, 2021).

1.7 Summary

This chapter has provided a brief overview of breast reconstruction in the United Kingdom, as a background for this thesis. Modern medicine, and much national and international healthcare policy, espouses the values of patient-centred care and shared decision-making. This is in part is due to the growing realisation that better patient outcomes and satisfaction with care are more likely if the patient is a participant in making decisions about what happens to them – ‘No decision about me, without me’ (Coulter and Collins 2011, Title page). Although the NMBR Audit showed reasonable levels of satisfaction, and good clinical outcomes, nevertheless significant variations in care were found. Inconsistency has been associated with lack of, or limited availability of reconstruction options, thereby narrowing the opportunity for patients to indicate preference. These issues with variation of care and lack of access to specialties persist despite the dissemination of best practice guidance in 2012 (MacNeill and Irvine, 2021).

Despite suggestions that patients’ priorities are commonly misunderstood (Mulley et al, 2012), utilisation of a patient-centred/shared decision-making approach should encourage identification of the patient’s preferences. However, breast reconstruction decision-making for women is complex and influenced by various factors, many of which are outside the remit of any doctor-patient ‘therapeutic alliance’ (Mead and Bower 2000, p 1090).   The combination of the availability of a range of available procedures, all with extensive clinical risks and benefits, must be balanced with individual patient suitability for a procedure. Clinicians have been reported to provide inadequate information for decision-making in breast reconstruction (Potter et al, 2015) and even guided selection towards the clinician's preferred procedure (Potter et al, 2013). I have also suggested that there may be communication biases within the surgical consultation, and also that clinicians may not completely comprehend why the women they encounter choose particular reconstructions. This myriad of influencing factors within the consultation is furthered by other factors, such as national cancer targets, access to specialist surgeons, a diagnosis of cancer (with concomitant existential concerns), loss of the breast (and associated body image change), and for some, assault on identity (or biographical disruption, [Lupton, 2012]). Collectively, this creates a highly nuanced and multi-layered process that women are by necessity required to navigate.

Given the complexity of this decision-making phenomenon, with its numerous influencing factors, it remains unclear what women perceive as important and motivates their choice of reconstruction. As the NMBR Audit identified, satisfaction with mastectomy, timing of reconstruction, and availability of the different types of reconstruction were variable, which justifies an exploration of what influences women's choice when selecting a type of reconstruction. Ultimately, a better understanding of why women choose reconstructive procedures could allow clinicians, and perhaps the breast reconstruction service as a whole, to better support women as they make a decision that will fundamentally change their body.

1.8 The Research Questions

The issues summarised in this introductory chapter led to the development of the overarching research question that served to drive this endeavour, namely:

> *What do women with breast cancer perceive as influential when choosing a type of breast reconstruction?*

As decisions are not taken without an underlying context, it is also important to understand the experience of choosing to have reconstruction:

> *What experiences were important to women with breast cancer undergoing mastectomy when choosing to have breast reconstruction?*

And finally, central to modern decision-making is the interaction between surgeon and the patient. It also seemed pertinent to explore in addition:

> *What do clinicians think is important to women, when choosing a type of breast reconstruction?*

To answer these research questions, I describe in Chapter 2 a review and synthesis of the available qualitative literature that addressed women's choices regarding reconstruction. Care was taken to identify the literature that examined choice of type of reconstruction, as the factors that influence choice whether to have a reconstruction (or not) have previously been well described in the literature (Flitcroft et al, 2017). The results of this synthesis were utilised to guide a qualitative interview study involving women who had been offered reconstruction, and clinicians involved in delivering breast reconstruction services.

Chapter 3 describes the methods utilised to undertake this study. It was decided to recruit clinicians, as well as women who had been presented with reconstruction options to be interviewed, in recognition that there are many contextual factors that could influence choice. Clinicians would be able to examine their experience of consultations where decision-making took place, and potentially describe the ways in which they might influence women's choices. The findings from the analysis of these interviews are reported, and interpretations presented in Chapters 4 and 5. These chapters seek to illuminate and offer a better understanding of what influences women as they choose a type of breast reconstruction. Finally, Chapter 6 will seek to contextualise these findings within the literature, further explore the discourses and metaphors shaping discussions of breast reconstructions, and make recommendations for clinical practice and further research.

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CHAPTER 2 – QUALITATIVE EVIDENCE SYNTHESIS

2.1 Introduction

This thesis focuses on the primary research question: *What do women with breast cancer perceive as influential when choosing a type of breast reconstruction?* A review of the available evidence was undertaken at the outset of this study to address this question. The aim of this review was to identify manuscripts that would guide the design and development of a study addressing the research question, which is described in the next chapter. In particular, this review aimed to extract and synthesise factors that appeared to be influential to women when choosing a type of breast reconstruction. These would contribute to the development of an interview schedule for the study described in Chapter 3. As a novice researcher, I also wanted to immerse myself in descriptions of the experiences of women choosing to have breast reconstruction in order to develop a better understanding, as preparation for the collection and analysis of interview data required for the study. This was of particular importance, as I had only experienced the breast reconstruction decision-making process from the perspective of breast reconstruction clinicians, and not of the women making these decisions. As discussed in Chapter 1, clinicians may not always able to accurately identify the treatment preferences of patients (see section 1.5.1). Lastly, this review aimed to provide assurance that there was a gap in the literature that warranted exploration.

The research question was best suited to exploration through a qualitative approach, as it is most appropriate to studying processes that cannot be quantified, such as the perceptions of decision-making processes (Pope and Mays, 1995). Initial searches of the qualitative literature discovered few studies that explored women's perceptions of making a choice between different types of reconstruction. The findings of the NMBR Audit (Jeevan et al, 2014) suggested further examination of the provision of choice to women seeking breast reconstruction was needed (see section 1.4.4 for in-depth discussion). Breast reconstruction decision-making is complex – women must navigate a landscape of intricate clinical information, national cancer targets, access to specialists, and possible communication bias or preference of surgeons. As this appeared to be a complex topic about which little was known from the initial searches, a review of the qualitative literature was devised, on the basis that qualitative methods are ideal when trying to understand personal meaning behind an experience, especially when this is an area about which little is known (Pope and Mays 1995).

2.2 Background

Systematic reviews were developed to provide up-to-date summaries of the current state of research knowledge of various topics including interventions, diagnostic tests, prognostic factors, as well as other health topics (Lasserson et al, 2021). They are of critical importance given how the amount of literature grows at an ever-increasing rate (Bastian et al 2010). The Cochrane Handbook for Systematic Reviews of Interventions states: "*A systematic review attempts to collate all the empirical evidence that fits pre-specified eligibility criteria in order to answer a specific research question.*" (Lasserson et al, 2021; section 1.1). The systematic review is considered the highest level of evidence due the methodological rigour required to provide a synthesis of evidence (Moher et al, 2015). Systematic reviews have been well-developed for synthesis of quantitative studies, including pooled statistical analysis (meta-analysis).

Despite the close association of the systematic review and the synthesis of quantitative research, there has been a growing trend towards usage of systematic reviews for the synthesis of qualitative studies, employing the same comprehensive search strategy to systematically collate and review the qualitative evidence (Harden et al 2004). Similar to the value of pooled quantitative data in systematic reviews, a greater understanding of individuals' and groups' beliefs, ideas, experiences and priorities in their healthcare can be established with the aggregation of primary qualitative evidence (Flemming et al 2019). This aggregated body of evidence can produce a new cumulative knowledge, greater than simply the findings of individual studies (Flemming and Noyes, 2021). As one of the aims of this chapter is to identify whether there is a gap in the literature, a systematic review is well suited to address this.

In this chapter, I will undertake a systematic review of the qualitative literature, answering the research question: *What do women with breast cancer perceive as influential when choosing a type of breast reconstruction?* The studies identified will then be synthesised using a technique called thematic synthesis (Thomas and Harden, 2008) – this will be described further later in this section. The preferred nomenclature of this overall approach (ie a systematic review and synthesis of qualitative studies), which will be utilised henceforth, is a 'qualitative evidence synthesis' (as per the Cochrane Qualitative and Implementation Methods Group); this is an umbrella term that amongst other descriptions, includes 'qualitative systematic review' (Booth et al, 2016).

The qualitative evidence synthesis has become an increasingly used technique in response to demand from healthcare and health policy, as it can complement the answers typically addressed by quantitative systematic reviews and randomised controlled trials (Flemming and Noyes, 2021). There is also an increasing call for rigour and use of guidelines to provide greater transparency in the process (Tong et al 2012, Lewin et al 2018).

There are critics of qualitative evidence synthesis, who argue that qualitative research is not meant to be de-contextualised, and findings are specific to a group of participants and their context (Thomas and Harden, 2008). Its proponents however argue that a great advantage of synthesised qualitative research is its transferability (Munthe-Kaas et al, 2020). Transferability is the application of research results to other contexts, in contrast to generalisability, which refers to the extension of research findings from the study population to the population at large. The transferability of findings from a qualitative evidence synthesis leads to many practical applications, including informing health policy and practice (Thomas and Harden 2008, Suri 2011, Tong et al 2012, Lewin et al 2018).

Synthesis approaches can be thought of on a spectrum between integrative (or aggregative/descriptive), for example summarising the extant data, and interpretive (or analytical), which can develop new concept and theory, something greater than the individual findings (Dixon-Woods et al, 2005, Booth et al, 2016). There are now over 30 types of qualitative evidence synthesis, however there are three recommended by Flemming et al (2021) for general use, as they are the best developed, in terms of technical guidance and frequency of use. These three recommended techniques have also been reproduced in the Cochrane Handbook: thematic synthesis, framework synthesis/best fit framework synthesis and meta-ethnography.

Typically, approaches to synthesis are based on methods of primary qualitative research analysis. Thematic synthesis (Thomas and Harden, 2008) uses techniques of thematic analysis (Braun and Clarke, 2006), and is a flexible, commonly used method that can be used to interpret both contextually ‘thick’ and ‘thin’ data (see eg Ponterotto, 2006). It has a clearly structured approach which leads to the development of both descriptive and analytical themes.. Researchers undertaking a thematic synthesis can take an integrative or interpretive stance, thereby allowing them to generate new theory if appropriate (Flemming and Noyes 2021).

Framework synthesis has its origins in framework analysis. It offers a more deductive approach, in which research findings are extracted and synthesised into an a priori framework. It also is a highly structured method, with the primary purpose of integration of what is happening in a particular setting, as opposed to generating theory. It can be used to incorporate both qualitative and quantitative evidence in its synthesis (Booth et al, 2016, Flemming and Noyes 2021).

Meta-ethnography (Noblit and Hare, 1988) was developed in the 1980s in order to synthesise primary qualitative research; it is based on ethnography. It involves the development of a comparative understanding by combining primary research. It is a primarily interpretive approach, aiming to generate theory (Flemming and Noyes, 2021). Epistemological considerations are of particular import in this approach, and studies included for synthesis should have a compatible approach (Booth et al, 2016); for example, descriptive studies may not be suitable for this type of synthesis, as meta-ethnographies typically compare and combine authors’ interpretations.

Generally, choice of one of these approaches is dependent upon several factors, which have been set out in the RETREAT framework (Booth et al, 2016): the Review question, Epistemology, Timeframe involved, Resources, Expertise, Audience and Type of data. The RETREAT framework promotes transparency in reporting; it is also recommended in The Cochrane Handbook for Systematic Reviews of Interventions (Noyes et al, 2021). Thematic synthesis (Thomas and Harden, 2008) was chosen as the methodology for the qualitative evidence synthesis undertaken as part of this study, and is described in further depth later in this chapter (see section 2.3.2).

In applying the RETREAT framework, it is worth explicating the approach to this review, which consequently informs the review question and epistemological standpoint. The aims of this review were to understand a complex phenomenon, to inform a qualitative study, and to identify a gap in the literature. These aims were best suited to an integrative approach, firstly as I sought to understand women's perceptions, as opposed to generating theory, prior to my study. Secondly, integrative approaches are associated with comprehensive search strategies, which are better suited to identifying gaps in the literature. In informing myself as the researcher, I aimed for an inductive approach, so data would be grounded in women's experiences, as a deductive approach (linked to framework synthesis) would have been founded on existing knowledge, e.g. my experiences in a breast reconstruction unit.

Considering its epistemological stance, as this thesis represents an applied healthcare orientated study, an overarching pragmatic interpretive framework was most suitable (further described in section 3.3.1). Therefore, an epistemologically inclusive approach was also intended for this review. Some exponents of approaches such as meta-ethnography take the position that only studies with a similar epistemological stance should be sampled (Booth et al, 2016). Use of thematic synthesis would ensure that fewer studies were excluded from searches on methodological grounds.

Regarding the timeframe involved, only meta-ethnography was identified as a potentially more time-consuming approach (Booth et al, 2016), however this factor did not significantly encourage choice of other approaches, at the outset of the undertaking of this review. The literature retrieved from initial searches was limited, which did not suggest that resources would be an issue.

Considering the expertise needed to conduct the synthesis, as a doctor in training at the time of the literature review, I possessed no prior background in qualitative research. However, support to undertake the review was provided by two experienced qualitative researchers (AL/GC). Therefore, the more technical approaches, demanded when using framework synthesis and/or meta-ethnography, were accessible to me. However, we agreed within the team that thematic synthesis was the best approach for this review.

In terms of audience and purpose, this thesis seeks to inform healthcare practitioners and may be more attuned to descriptive approaches; both thematic synthesis and framework synthesis met this criterion. Lastly, the type of data that may be encountered should be addressed. Briefly, thick data can be described as data with sufficient context (ie data relevant to whom, and why) whereas thin data carries no contextual information (Booth et al, 2016). Where thick and thin data may be used, an approach with the flexibility to integrate both was desired, which again pointed towards thematic synthesis and framework synthesis.

Ultimately, a pragmatic, flexible, integrative approach was desired, which excluded as few studies as possible (given the limited results from initial searches). Thematic synthesis and framework synthesis both met these criteria. Framework synthesis offered a deductive rather than inductive approach however, so thematic synthesis was chosen in the end (Booth et al 2016).

A notable element of difference between the conduct of integrative and interpretive approaches to qualitative evidence synthesis is the decision regarding search strategy, with some arguing for a purposive approach. Purposive sampling is a type of non-probability sampling used in qualitative research, in which judgement is used to choose specific cases that promote conceptual understanding (Ames et al, 2019). Sampling in qualitative studies is meant to be 'informationally' representative, as opposed to statistically representative (Carroll 2017). Suri (2011) has suggested many approaches to purposive sampling of studies for inclusion in qualitative evidence synthesis, arguing for its value in interpretive methods. Integrative approaches however are generally associated with a comprehensive, exhaustive search strategy (Booth et al, 2016). As thematic synthesis was chosen, and one aim of the study was to identify a gap in the literature, a comprehensive search strategy was utilised.

A qualitative evidence synthesis (Noyes et al 2021), includes the following steps:

i) Development of a review question
ii) Searching for qualitative evidence

iii) Assessment of methodological strengths and limitations
iv) Selection of studies to synthesise
v) Selection of a qualitative evidence synthesis as well as data extraction method

These steps will be described in further depth in the following sections.

In summary, qualitative evidence synthesis (or qualitative systematic review) is a valuable form of evidence review. It has practical application in informing healthcare policy and clinical guidelines, just as the traditional quantitative systematic review does. The major qualitative evidence synthesis techniques have been described and introduced, and I have clarified my reasoning for choosing thematic synthesis, in line with the RETREAT framework (Booth et al, 2016).

2.3 Method

The research question formulation framework is important in qualitative evidence synthesis, in the development of search terms to plan a search strategy. The formulation framework used as a guide was the SPIDER framework, which may be more appropriate for a qualitative synthesis than the traditional PICO search strategy, by providing extra context of setting to refine search results (Cooke et al, 2012). More recently, the PerSPeCTiF framework (Booth et al, 2019b) has been suggested by The Cochrane Handbook for Systematic Reviews of Interventions as it provides a further element of refinement in time/timing. This was not used for guidance as it was published after the search strategy for this review was began.

The original research team (DL/AL/GC) agreed upon eligibility criteria for inclusion in the review, which included peer-reviewed manuscripts that: were written in the English language; were qualitative studies in design (involving interviews only, to provide as ‘rich’ data is possible); undertook original empirical investigation; and reported factors that influenced patient choice of type of reconstruction (as opposed to solely choice to have reconstruction). The tentative search terms based on the aim of the study and inclusion criteria can be visualised below, see Table 2.1 below.

Table 2. 1 – Research Question Formulation Framework (Cooke et al, 2012)

SPIDER	Search Terms
S - Sample	“wom*” OR “breast” OR “mastectomy”
PI – Phenomenon of Interest	reconstruct*
D - Design	“interview”
E – Evaluation	“deci*” OR “perce” OR ”experien*” OR “cho*”
R – Research type	“qualitative”

Initial searches run through MEDLINE and CINAHL databases found many women’s health topics unrelated articles to breast reconstruction, due to the search terms of the ‘evaluation’ heading, and the search term of ‘wom*’ (indicating women). So it was agreed to remove these terms, to refine the search. The term “(breast OR mastectomy) AND reconstruct*” served to identify all breast reconstruction studies, and the term “(qualitative OR interview)” was used to identify any study that incorporated qualitative methods or interviews. Together, these formed the search query: “(breast OR mastectomy) AND reconstruct* AND (qualitative OR interview)”.

The writing of this chapter began in September 2015, at the outset of this study. As such, initial searches encompassed the period between 1990 and 2015. The initial submission date of this thesis was intended to be in 2020, so the end date of the period for the final search was extended to 2019, to include the period from 1990 to 2019. Final searches were re-run before resubmission of this thesis. This period was chosen for two reasons. Firstly, the DIEP flap reconstruction (the most recently developed breast reconstruction technique) emerged more frequently in the early 1990s (Allen et al 1994). Secondly, Reaby’s seminal qualitative work exploring breast reconstruction decision-making, describing reasons why women have reconstruction, was published in 1998. Therefore, it was thought that 1990 would be a safe year to use as the period start date, as the three reconstructive modalities introduced in the NBMR

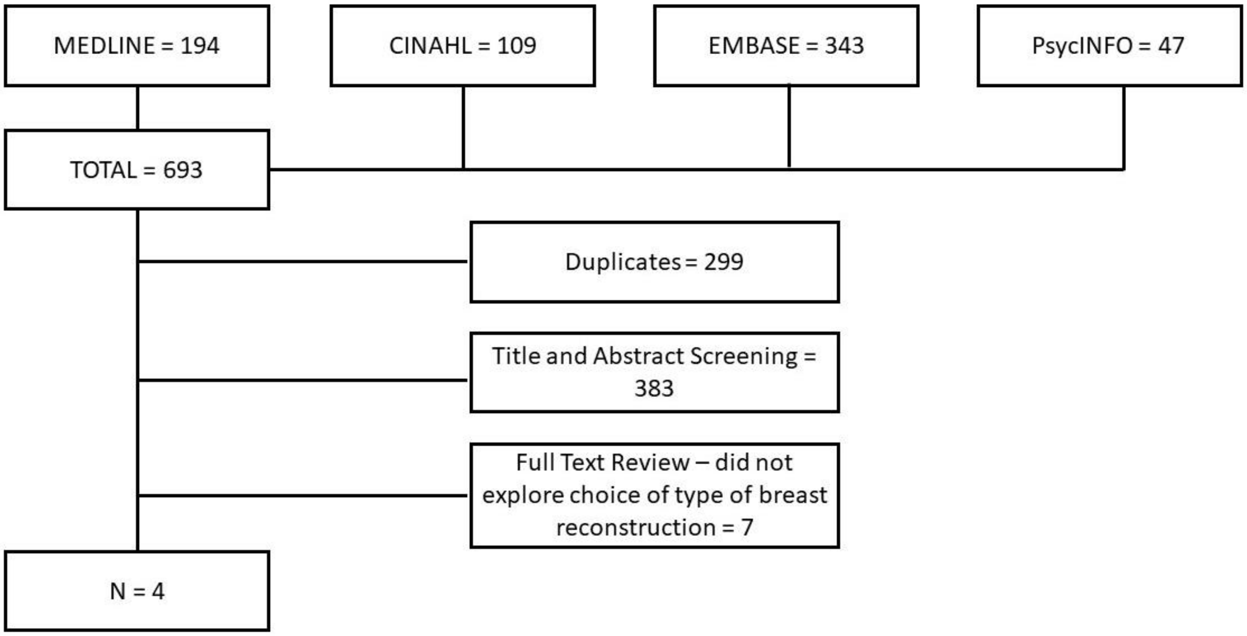
Audit were not in routine use, and therefore would not be the focus of qualitative research prior to this date.

2.3.1 Search of the Literature

The databases through which the search query was run included MEDLINE, CINAHL, EMBASE and PsycINFO. MEDLINE and CINAHL were chosen as they represent the most widely used databases for qualitative publications, particularly in medicine, nursing and healthcare; they typically suffice for most healthcare related questions (Cooke et al 2012, Flemming and Noyes 2021). Many qualitative studies are indexed in PsycINFO and EMBASE (Cooke et al, 2012), therefore, these were also searched.

The databases were searched via the NICE Healthcare Databases Advance Search tool, which yielded 194 citations from MEDLINE, 109 citations from CINAHL, 343 citations from EMBASE and 47 citations from PsycINFO, amounting to 693 identified articles. De-duplication was performed by DL through the database tool, removing 299 articles. Following this, identification of eligible manuscripts was approached in accordance with the PRISMA statement (Liberati et al 2009). Title and abstract screening were undertaken by DL and CL (a GP trainee with research experience) and 11 records were retained. Any uncertainty concerning inclusion or exclusion of a study after review of the title and abstract was re-examined in the next stage of the process, involving full text review (DL). Following this, 11 full-text articles were assessed for eligibility, yielding four studies for inclusion. The excluded studies explored the decision to have a breast reconstructed, or timing of reconstruction, but did not meet inclusion criteria as they did not explore choosing a type of breast reconstruction. Note was made of Lee et al’s (2010) and Flitcroft et al’s (2019) studies which did make reference to choice of type of reconstruction in the abstract, but upon full text review provided no rich description of choice of type of reconstruction. These four studies were reviewed within the original research team (DL/AL/GC), to ensure they met eligibility criteria and were of satisfactory quality. See Figure 2.1 for the PRISMA Flow Diagram and Table 2.2 for a summary of the four studies included.

Figure 2. 1 – PRISMA Flow Diagram



2.3.2 Data Extraction, Appraisal and Synthesis

Characteristics from each of the four included studies, such as study location, sampling, participant characteristics, analytical method and study focus were extracted (see Table 2.2 below). The quality of each of these studies was then appraised (DL), utilising the Critical Appraisals Skills Programme Qualitative checklist (CASP 2018), which assesses various study components including the description of the study's purpose, methodological rigour, ethics, and reflexivity, through a checklist of ten questions. Appraisal using the CASP Qualitative checklist (2018), found that two of the four studies included (Potter et al 2013, and Rubin et al 2013) met all ten criteria. The remaining two studies (Gopie et al 2011, and Boehmer et al 2007) reported on nine of the ten criteria; evidence of reflexivity, the relationship between the researcher and participants, was omitted from these reports. Overall, it was decided within the research team that all four studies were of satisfactory quality for inclusion in the synthesis.

A summary of the pooled demographics is depicted below in Table 2.3. Across all four studies, 104 women participated. Two of these studies took place in the United States, one in the Netherlands, and one in the UK. Mean and median ages ranged from 46.4 to 52.7 years of age, however some recorded age at time of operation and others at the time of interview. Rubin et al (2013) did not record which types of reconstruction the participants chose, however evidence from informant quotations does express preference or choice of types of reconstruction.

Study findings were analysed and synthesised using thematic synthesis (Thomas and Harden 2008). As with most synthesis methodologies, thematic synthesis translates aspects of a technique for primary qualitative research, in this case thematic analysis (Braun and Clarke, 2006). Thomas and Harden (2008) describe the process of thematic synthesis as follows. Firstly, a decision was made as to which data to extract, as key findings can be presented quite differently in studies, due to varying reporting styles. This technique views all study findings for extraction of data as any text labelled as 'results' or 'findings' in the report – this includes both participant quotations and any interpretation. Following this, synthesis took three steps, between which there was significant overlap. The first stage involved line-by-line coding of the extracted text, which facilitated one of the most important functions of a synthesis – the translation of concepts across studies (Thomas and Harden 2008). Codes were developed by myself, and then reviewed within the team (DL/AL/GC). Each code represented an aspect of women's decision-making which ultimately influenced the type of breast reconstruction chosen. All text linked to a code was then reviewed for consistency.

The second stage involved the inductive development of descriptive themes. Similar codes were grouped to form a hierarchal structure, with descriptive themes (that connect these groups of codes) forming a row above. The third stage described the generation of analytical themes. It is at this stage that the synthesis takes on its primary role, in 'going beyond' the content from which it was derived (Thorne et al, 2004), and is similar to 'third order interpretations' in meta-ethnography (Britten et al, 2002, Thomas and Harden 2008). It is a cyclical process where an analytical theme is developed if it can be inferred as an overarching answer to the research question and accounts for the descriptive themes. This stage of the synthesis was iterative and involved the research team (DL/AL/GC), as at this stage more abstract themes are developed requiring agreement. Synthesis of these studies yielded 34 codes, used to develop 21 higher level codes across all the studies, then 13 descriptive themes and finally six analytical themes (see Appendix 1). These analytical themes were interpreted as overarching themes that serve to answer the research question.

2.4 Results

The four studies that were eligible for inclusion in this synthesis are summarised below in Table 2.2.

Table 2. 2 – Study Characteristics

Authors	Location	Sampling	Methodology	Method	Themes Identified
Potter S et al 2013	United Kingdom	Purposive: maximum variation followed by theoretical. 31 women, 35 healthcare professionals	Grounded theory	Constant comparison technique of grounded theory (Glaser and Strauss, 1967) Semi-structured interviews	1. *Participants' perceptions of access to care and the provision of choice* 2. *Lack of information and time for decision making* 3. *Mismatches between patients' desired and actual involvement in decision making* 4. *Service provision and organisation of care* 5. *Interventions to improve choice: enhancing collaboration, communication, and access to care*
Rubin L et al 2013	United States	Stratified purposive sampling. 27 African American women	Grounded theory	Grounded theory (unspecified) Semi-structured, open ended,	Reasons for not having breast reconstruction 1. *Implants and medical (mis)trust* 2. *Body ethics*

				face to face interviews	<u>Reasons for electing breast reconstruction</u> 1. *Feeling normal* 2. *Age* 3. *Appearance* 4. *SES and insurance coverage*
Authors	**Location**	**Sampling**	**Methodology**	**Method**	**Themes Identified**
Gopie JP et al 2011	Netherlands	Purposive sampling. 16 women who had DIEP and 15 women who had IBR	Hermeneutic phenomenological approach	Thematic analysis (unspecified) Semi-structured, open ended interviews	<u>Reasons for choosing to have BR</u> 1. *too young to live without breasts* 2. *avoid external prosthesis* 3. *to feel 'more free and self-confident'*

					4. *femininity* 5. *above all, to feel normal* Reasons for choosing IBR 1. *Surgical considerations* (short recovery period, smaller impact of surgery, regain daily life as soon as possible, short anaesthesia period, insufficient bodily tissue) 2. *Aesthetics* (number of scars, particularly avoidance of donor-site scars) Reasons for choosing DIEP 1. *Surgical considerations* (felt lowest complication risk, long-term benefits in avoiding IBR – such as capsular contracture and malrotation, abdominoplasty, IBR contraindicated due to radiation) 2. *Aesthetics* (preference for own tissue as it would feel soft and look natural, anticipated that the DIEP reconstruction would sag like their own contralateral breast – as opposed to IBR) 3. *Sexuality* (hope that the DIEP would improve sexual relationship with partner, increased confidence in sexual contacts)

Authors	Location	Sampling	Methodology	Method	Themes Identified
Boehmer U et al 2007	United States	Purposive: Community-based sampling of 'sexual minority women' with further snowball sampling 8 women chose BR, 7 women who declined BR. Sexual minority included lesbian and bisexual women. Partner interviewed as well.	Grounded theory	Grounded theory (Strauss and Corbin, 1990) Semi-structured, narrative interviews	Overarching themes (regardless of choice) 1. *Breast size* Women with small breasts were comfortable with rejection of BR. Large-breasted women struggled with the implications of mastectomy, some of whom chose reconstruction in combination with reduction. 2. *Association of the breast with self-image* Not being defined by having breasts was closely aligned with a 'sexual minority' (ie lesbian identity). 3. *Body strength and physical functioning* Body strength and physical functioning were more important considerations than aesthetic considerations. 4. *Body image and values*

					They noted their ‘otherness’ – the discrepancy of their values and body image with those of mainstream society. Avoiding compromising ‘healthy’ body parts – either by declining reconstruction or declining a reconstructive modality with a donor site. 5. *Relationship status* <u>Choosing against reconstruction</u> *Women who decided against reconstruction emphasised strength, long-term health, and survival, rather than fitting a stereotypical beauty ideal.* <u>Choosing to have reconstruction</u> 1. *Avoiding depression* 2. *Regaining a ‘normal’ appearance* 3. *Covering up the physical effects of cancer*

Table 2. 3 – Pooled Study Demographics

Study Number (from Table 2.2)					
	Potter et al 2013	**Rubin et al 2013**	**Gopie et al 2011**	**Boehmer et al 2007**	**Overall**
Country	UK	US	Netherlands	US	
Number of Informants	31	27	31	15	104
Age	51 (median)	52.7 (mean)	46.4 (mean)	52.3 (mean)	
Reconstruction	31	12	31	8	82
No reconstruction	0	15	0	7	22
Type of reconstruction:					
IBR	11	Not Recorded	15	5	31
LD	10	Not Recorded	0	0	10
TRAM/DIEP	11 (DIEP)	Not Recorded	16 (DIEP)	3 (TRAM)	30
Relationship Status	26 Married 1 Single 4 Divorced	10 Married 13 Single 3 Widowed 1 Unknown	27 Partner	12 “Supports”	
Highest Level Education	Compulsory education only 16 Further education 15	Not recorded	5 ‘Low’ 14 ‘Intermediate’ 12 ‘High’	High School – 0 College – 6 Graduate School - 12	

2.4.1 Comment on Study Characteristics

All four studies were qualitative in design, and all employed semi structured interviews. Three studies (Boehmer et al 2007, Potter et al 2013, Rubin et al 2013) were analysed using grounded theory, whilst Gopie et al (2011) adopted a phenomenological hermeneutical approach with thematic analysis. Each of the four studies employed purposive sampling. Potter et al (2013) followed on maximum variation sampling with theoretical sampling, whilst Boehmer et al (2007) followed on community-based sampling with snowball sampling. The participants recruited to two of these studies could perhaps limit transferability, as one study focused on the views of African American women (Rubin et al 2013), and another focused on the views of 'sexual minority women' in the United States (Boehmer et al 2007). Boehmer et al (2007) defined 'sexual minority' as women who identified as lesbian or bisexual, or had a female partner.

2.4.2 Themes

Six themes were developed from the synthesis of these four studies. They were entitled *Appearance, Return to Normal, Natural, Perception of Reconstructive Risks, The Surgical Consultation,* and *Body Ethics.* Each of these themes represented a concept or experience that influenced women to have a particular type of breast reconstruction.

2.4.2.1 *Appearance*

From the included studies, appearance was evidently an important aspect to women when deciding on whether to have reconstruction at all and if so, which type. It implied aesthetic concerns to some, i.e. what the breast and body looked like, but for others appearance was connected to the conceptualisation of self. When interpreted from an aesthetic standpoint, the appearance of the breast represented a significant domain of influence as described by the women of Rubin et al's study (2013).

> *"I always said if I ever get breast cancer, I wouldn't go with any reconstruction… But what made me change my mind was my breast is so large… just to have one, it's too unbalanced"* (Rubin et al 2013; p1111)

In this example, the importance of a sense of balance appeared to influence choice to have breast reconstruction, even when before breast cancer, reconstruction was not desired. The appearance of the breast, and its function in shaping the clothed body, was also described as a motivation for breast reconstruction (Rubin et al 2013).

The symmetry of the post-operative breast was reported to contribute to decision-making when choosing a reconstructive modality.

> *"With silicones, at the age of 80… I'd probably end up with one pretty breast, while the other would be hanging down like a teabag. That would be no good!"* (Gopie et al, 2011; p 1065)

This extract underscores how women are considering life beyond breast cancer in their decision-making. In this example, this led to choice of DIEP instead of IBR, as in the long term it would accommodate the natural 'sag' of the healthy breast that occurs with ageing. Interestingly, symmetry was more important than having a 'pretty breast', which suggests a preference for looking normal for one's age. The DIEP presented other decisive post-operative aesthetic features in that the extensive post-operative scarring associated with the DIEP served to discourage, whilst the benefits of the abdominoplasty represented added value to the procedure (Gopie et al, 2011).

2.4.2.2 *Return to Normal*

References to a state of 'normal', and a desire to return to 'normal', were a recurring narrative in these studies, yet there were multiple interpretations of what constituted normal.

> *"I wanted the freedom of being able to pass if I needed to; of being able to be in public, and not be a cancer person"* (Boehmer et al, 2007; p468)
>
> *"Just to look normal again… like a normal human being and not some freak animal… when [you're] naked and looking at the mirror, you don't see the same person… It takes a toll."* (Rubin et al, 2013; p1109)

The desire to appear normal when in public has been alluded to above in the discussion of appearance. These extracts however suggested a psychosocial concern beyond appearance, that was connected to cancer, and not being seen as someone with a possibly stigmatised condition.

These suggest a return to a normal sense of self-concept, and interacting normally with others. These views appeared to motivate women to have reconstruction.

Normality was also rooted in function, in the ability to perform daily activities and daily responsibilities.

> *"To undergo breast reconstruction with bodily material is more complex than implant reconstruction, the recovery period is longer and more intense, and given my social circumstance with three little children… Being out of daily routine for weeks already is inefficient, not to mention a recovery period of months!" (*Gopie et al, 2011; p1065)

A desire for normality was a factor when choosing to have a particular type of breast reconstruction as well: some women favoured IBR as it was linked to a swifter return to normality.

2.4.2.3 *Natural*

In three studies (Rubin et al, 2013, Potter et al, 2013, Boehmer et al, 2007), implant-based reconstructions were perceived as unnatural. For some, this discouraged choice of IBR, due to views of the breast implant as artificial (Boehmer et al, 2007) or foreign (Rubin et al, 2013).

> *"I don't believe in implants…I don't want anything foreign in my body that I don't need foreign."* (Rubin et al, 2013; p 1107)

For others, this was implied retrospectively after having noted a less than natural look of IBR, hoping for a natural 'droop' (Potter et al, 2013). Preference for this type of natural reconstruction (with the form and 'droop' of a pre-treatment breast), motivated choice for DIEP in Gopie et al's (2011) sample, along with expectation of a natural-feeling (to touch) reconstruction.

Conversely, some women considered all reconstructions as feeling and looking fake, and consequently linked 'natural' to complete refusal of reconstruction in its entirety (Rubin et al, 2013). However, in Rubin et al's (2013) study, being natural was very much connected with religious faith. This study focused on accounts of African American women in the United States, whose religious beliefs strongly influenced how 'being natural' was understood.

> *"Why take some part of me, to relieve something that was taken away that God says has to be gone"* (Rubin et al, 2013; p1108)

> *"Use me. Use my flesh… Give me the natural thing. Use what God has given me, use whatever tissues, take it from the thighs, take it from the back, use my stuff… I don't' want nothing, no more foreign stuff put in me."* (Rubin et al, 2013; p1108)

Having to make this choice provoked intense religious study for some participants. Some expressed a belief that it was 'God's will' that they had needed a mastectomy, therefore reconstruction was not an appropriate option. Others argued that a reconstructive approach that incorporated existing tissue (viewed as natural) was sympathetic with their beliefs, because it was originally given by God. Some women in Potter et al's (2013) study also associated breast implants with cosmetic improvement and television personalities. This led to immediate dismissal of this type of reconstruction. Other negative views of implants that discouraged choice of IBR included being 'false' and disparagingly described as 'plastic' (Potter et al, 2013).

2.4.2.4 *Perception of Reconstructive Risks*

Women's views of the risks of reconstructions varied; these perceptions were often instrumental when choosing a type of reconstruction. The main concerns were linked to operative risk, complications and safety. Some opted against IBR due to their perception that the implant would need replacing at some point in the future, or worries about capsular contracture and malrotation occurring (Gopie et al 2011). Due to these concerns about further procedures, some described the DIEP as a safer option (Gopie et al, 2011), despite the procedure being associated with increased overall surgical risk. Indeed, for some, a preference for autologous reconstruction could not be realised due to increased operative risk for some women, in the context of their underlying comorbidities (Rubin et al, 2013). Others chose the implant-based reconstruction due to the shorter recovery period, with a decreased post-operative impact (Gopie et al, 2011). Beliefs that implant-based reconstructions might burst and leak chemicals, or that implants obscure detection of cancer recurrence also discouraged choice of IBR (Rubin et al, 2013).

2.4.2.5 *The Surgical Consultation*

Varying aspects of the surgical consultation itself influenced women's choices. Women in Potter et al's (2013) study discussed lack of satisfaction with the surgical consultation;

specifically, inadequate information provision, restricted choice, and little time to make decisions. Dissatisfaction with the surgical consultation was linked to post-operative regret, i.e. knowing that they would not have chosen a specific reconstruction, had all options been adequately explained or explored.

> *"I mean really he just explained what they could do for me an'… I just had to say yes or no… Different ways weren't discussed at all… so I just went along with it 'cause I thought that was the only thing you could have done. I did find out later that you could have the stomach muscles used etc which I think I probably would have gone for… I would rather have had my own body parts than plastic"* (Potter et al, 2013; p1185)

The perception of possible bias towards a particular procedure was also described in relation to other members of the breast reconstruction service. Some of the participants in Potter et al's (2013) study based in the UK, reported that they had been directed towards particular procedures.

> *"Well, it [an abdominal flap] was mentioned… but when I was talking to the [breast care nurse], it was kind of like I was steered… to the [LD-flap]… that was not my only option, but it was the option I was being swinged towards."* (Potter et al 2013; p1183)

As this excerpt does not include clinical context about this woman's particular situation, it is difficult to be certain if this represented an opinion based on an underlying clinical rationale or personal perception of the nurse. However, a preference for autologous reconstruction at their particular unit is suggested by one of the plastic surgeons interviewed by Potter et al (2013). Another plastic surgeon also discussed the limited choice provided by local oncoplastic breast surgeons:

> *"We do have three breast surgeons in the area who just basically they tell the patients what's going to happen to them. They all just get latissimus dorsis… There's no real choice… there is a hammer and there is a nail and that's all there is to it."* (Potter et al, 2013; p1185)

In contrast, in the same study, an oncoplastic breast surgeon had a similar view of a local plastic surgeon.

> *"Everybody has to be painted into a DIEP flap… There's a little bit of prejudice and lack of touch of reality going on. 'If you've got a hammer everything looks like a nail!' – well, I think the DIEP at the moment is the hammer and I think other very good*

> *techniques of reconstruction are being cast aside for political reasons rather than for actual practical reasons."* (Potter et al, 2013; p1186)

While restriction of choice for women was cited for clinical reasons in other studies (Rubin et al, 2013), suggestions from surgeons recruited by Potter et al (2013) suggest that preference of clinicians may also have a role in this.

A different impression of the surgical consultation was noted in Boehmer et al's (2007) study of women who identified as lesbian and bisexual. One participant recalled how the consulting surgeon concentrated on the cosmetic aspects of the reconstruction rather than her own concerns.

> *" The whole decision… was such a weird experience for me… all these things that didn't make any sense to me. They were talking about what it looked like, they were talking about droop… I don't care about droop. Tell me how it affects my body… Will I be able to move… whether it was skiing or golf or… running around… I don't care about the cosmetic side. It's not important to me. And they couldn't, like, get beyond that. And I realized I didn't need to talk to them, because I didn't need reconstruction, because I didn't care about that"* (Boehmer et al, 2007; p467)

In this case, the surgeon did not appear to take time to assess the individual needs of the participant which appeared to contribute to choosing not to undergo reconstruction. Whereas in a different study (Rubin et al, 2013) a woman described how a surgeon questioning her decision led to a change of treatment preference.

> *"I think my doctors… one sat down, he said, 'Listen, you are a young lady. Summertime is coming. You may think now that it doesn't matter, but it is going to matter to you once summer is here and you can't wear that red tank' … I thought about it and I said yeah, I think he's right… I didn't think it mattered, but I'm glad I'm doing it"* (Rubin et al 2013; p1111)

These extracts suggest an approach to the consultation that was driven more by the surgeon's constructs of what breast reconstruction means to a woman. These accounts do not suggest patient-centredness, as it seems that these women's personal preferences were overlooked. Although both these studies were based in the United States, patient-centred care has been advocated by the (former) Institute of Medicine (IOM) in the USA since the early 2000s (IOM, 2001 – see section 1.5.2).

2.4.2.6 *Body Ethics*

A key concept found in this thematic synthesis is that of body ethics, which is described by Rubin et al (2013) as a set of values and core beliefs about care and treatment of the body, guiding the types of procedures women would accept. For the participants in her study Rubin et al (2013), this identified a set of values that included a preference for natural processes, aversion towards 'foreign' implants, and an emphasis on pureness and divinity of a body given by God; these values influenced women's choice to either have autologous reconstruction, or refuse reconstruction altogether. This type of body ethics appeared to be grounded in the culture of the African American women studied, and linked by the authors to positive body image and body acceptance. For example, when asked why African-American women had lower rates of breast reconstruction, participants explained their thinking by contrasting what they perceived were differences in body acceptance between themselves and white women:

> *"White women… they always get implants of some sort. They always want bigger breasts, cause the white male, that's what they look at… in the black community the butt is the centre of attraction… they're not looking at your breasts."* (Rubin et al 2013; p1107)
>
> *"Black people are just more satisfied with their appearance than white people… we're more forgiving."* (Rubin et al 2013; p1107)

These extracts suggest also suggest different cultural views of the sexualised body, and an ethical dimension. This cultural aspect of the concept of body ethics may be explained by its origins in Rubin et al's study (2003) of eating disorders in African-American and Latina women. In this study, participants recognised and appreciated the beauty of a diverse range of body types, rather than simply endorsing what they saw as the stereotyped dominant culture – the thin, svelte and lean body. These women articulated a body ethic of 'self-acceptance and body nurturance, reject[ing] the dominant cultural ethos that encourages women to reshape their bodies to emulate the cultural ideal' and 'encompass[ing] a broader interest in health and wellbeing' (Rubin et al, 2003; p 70). They vigorously defined their own aesthetic, incorporating personal values, representing well-being. This suggests varying types of body ethic across different groups.

Although they did not use the same terminology, I suggest that Boehmer et al (2007) describe a set of values and core beliefs about the treatment of the body, expressing a different body ethic, in their study of women who identified as lesbian and bisexual.

> *"… lesbians sometimes have different views about body image that are different from – what do you call it? – straight world"* (Boehmer et al. 2007; p467)

The authors described a dissonance between the values of the 'sexual minority' and those of mainstream society. For these participants, the breast was political. Body image was rooted in sexual orientation, and linked to an expectation that the individual's self-concept was not defined by their breasts (Boehmer et al, 2007). They suggested that the women in the study espoused a value system that prioritised body strength and physical functioning over aesthetic concerns in reconstruction. This was well represented by Boehmer et al's (2007) extract in the previous section, in which a woman declined reconstruction, partly due to the fact that it did not provide a functional benefit. These values did not only entail declining reconstruction.

> *"…there were either two kinds of reconstruction surgery that can be done; one is put in the expander the other is the transflap when they use some tissue from the stomach or your back. And that I knew I definitely did not want to do. I didn't want to mess up other parts of my body that were basically OK. So I decided to do the tissue expander and have an implant put in"* (Boehmer et al, 2007; p468)

Women also declined autologous reconstruction, on the basis that it caused damage, or reduced function of otherwise healthy areas.

2.5 Discussion

Six key elements that influence women when choosing to have a type of breast reconstruction were identified in this qualitative evidence synthesis: *Appearance; Return to Normal; Natural; Perception of Reconstructive Risks; The Surgical Consultation;* and *Body Ethics*. An aim of this synthesis was to develop an understanding of what influenced women when they chose a type of breast reconstruction. This process was invaluable to me, encouraging a broader appreciation of women's perspectives of the breast reconstruction decision-making phenomenon, which I believe improved my ability to interview them, and analyse their accounts. Another aim of this synthesis was to guide the development of an interview schedule. The findings of this synthesis did somewhat inform the development of an interview schedule – this is discussed in more detail in section 3.7.2. The final aim of this synthesis was to assess whether there was a gap in the literature; this is discussed in depth in section 2.5.2 below.

This synthesis yielded interesting findings, important for understanding the experiences of women when choosing a type of breast reconstruction. The first four themes (*Appearance; Return to Normal; Natural; Perception of Reconstructive Risks*) were not unexpected, given my experience working in breast reconstruction. In addition to this, the great influence of the surgeon on choice of reconstruction has been highlighted; this warrants further examination and justified the decision to interview clinicians as part of the qualitative study. An important finding is that decisions can be influenced by what women perceive is viewed as normal by others, or even society at large; this is supported by the literature (Denford et al, 2011). The theme of *Body Ethics* is a key contribution of this synthesis, which highlights the importance of wider value systems held by women, and how they can affect choosing a type of breast reconstruction. For example, in Boehmer et al's (2007) group of women who identified as lesbian or bisexual, some were more likely to decline breast reconstruction due to a distinct value system, whilst in Rubin et al's study (2013) African-American women stressed the difference between their own approach and that of White American women. However, the transferability of these findings to a UK context is uncertain; this is described further in section 2.5.2 below.

2.5.1 Rigour and Limitations

Evidence of rigour, or the 'trustworthiness' of study findings, is increasingly important in qualitative evidence synthesis, just as it is in other qualitative research methods. The suggested tool (by the Cochrane Handbook for Systematic Reviews of Interventions) for providing evidence of rigour is the GRADE-CERQual assessment (Lewin et al, 2018). It is an emergent technique that Lewin et al (2018) state guides as to how much confidence should be placed in findings of a qualitative evidence synthesis: 'an assessment of the extent to which a review finding is a reasonable representation of the phenomenon of interest' (p1). It does not involve a numerical scoring, just an assessment of the degree of overall confidence in the review, ranging from high to very low. Each review finding is assessed based on four components: methodological limitations, coherence, adequacy of data, and relevance, rated on a scale from ‘no concerns’ to ‘serious concerns’. With pragmatism in mind, these four components will be used as a guide to discuss how rigour was considered throughout this study.

Methodological limitations (Munthe-Kaas et al, 2018) refer to the quality of the included studies, as confidence in a synthesis is predicated on the quality of the included studies. The CASP Qualitative checklist (2018) has been utilised as above, with all studies meeting high enough standards (see section 2.3.2). Assessment of coherence (Colvin et al, 2018) considers how well review findings fit with the primary studies. It is understood that more interpretive studies may depart from the findings of primary studies more than integrative studies, which is also what makes them valuable. Nonetheless, this study was descriptive in approach, with manuscripts coded inductively, therefore themes were checked within the team (DL/AL/GC) during initial analysis, to ensure they were represented by the primary studies and extracts presented. The third component is the assessment of data adequacy (Glenton et al, 2018), which refers to a satisfactory number of studies leading to each review finding (a proxy for the number of participants generating this data). There were only four studies included; this may raise concern as the *Body Ethics* theme is based on accounts from only two studies. The rest of the themes are based on three or all four studies. However, lack of data adequacy can also suggest that there is not enough primary research in the field, which is perhaps likely given the aim of this thesis and the four included studies. Lastly, relevance (Noyes et al, 2018) assesses how well data from the studies support review findings in the context of the research question. Comparing studies against the SPIDER framework (see section 2.3), two studies could be seen as partially relevant, as they specified two subgroups of women as opposed to women generally. Otherwise, all studies were directly relevant to the other contextual elements of the search. Overall, the GRADE-CERQual assessment was used as a guide to a discussion of rigour in the conduct of this study, and no major concerns were noted.

In keeping with the increased call for transparency in the conduct of qualitative evidence synthesis, I also present the ENTREQ statement, which guides the reporting of these techniques – see Table 2.4 below (Tong et al 2012).

Table 2. 4 – ENTREQ Statement (Tong et al, 2012)

No	Item	Section
1	Aim	2.1
2	Synthesis methodology	2.2, 2.32
3	Approach to searching	2.2, 2.3.1, 2.3.1
4	Inclusion criteria	2.3
5	Data sources	2.3.1
6	Electronic Search strategy	2.3
7	Study screening methods	2.3.1
8	Study characteristics	2.4
9	Study selection results	2.3.1
10	Rationale for appraisal	2.3.2
11	Appraisal items	2.3.2
12	Appraisal process	2.3.2
13	Appraisal results	2.3.2
14	Data extraction	2.3.2
15	Software	N/A
16	Number of reviewers	2.3.2
17	Coding	2.3.2
18	Study comparison	2.3.2
19	Derivation of themes	2.3.2
20	Quotations	2.4
21	Synthesis output	2.4

2.5.2 Review Findings in Context

The transferability of the findings of this synthesis to a UK context warrants some discussion. The two US based studies focused on the experiences of women with specific characteristics, namely African-American and lesbian and bisexual women. The way in which American women access and finance healthcare is different from the UK, and this may influence perceptions of breast reconstruction, particularly given variations in health insurance coverage (NCI, 2017). The findings illustrated different values underpinning these decision-making groups, and described beliefs contrasting with those perceived to be held by heterosexual or White women. This was explained conceptually as different types of body ethics. The experience of Rubin et al's (2013) group of African-American women also described how their faith framed their decision-making. Findings from these groups may therefore be transferable to very specific UK healthcare contexts, but it is unclear whether these findings would be relevant to the UK healthcare setting at large. However, in this thesis 'body ethics' formed a 'sensitising concept' (Blumer, 1954) which, while not formally guiding analysis, resulted in being more attuned to the influence of women's value systems on decision-making.

One study was from the Netherlands (Gopie et al 2011). The research aims in Gopie et al's study (2011) were similar to those explored in this thesis. The research was limited to a comparison of motivations for choosing DIEP or IBR, and not the LD. This is in keeping with contemporary clinical practice, as the LD is being performed much less frequently (see section 1.6). Findings established from this study are likely to have some resonance given other similarities, such as universal health coverage for breast reconstruction. However recent evidence suggests that women of low socioeconomic status in the Netherlands are less likely to receive immediate breast reconstruction (Felipe et al, 2021). Also, the authors provided just five quotations, and therefore there was not a significant amount of rich data to draw upon for analysis and synthesis.

Only one of the four studies (Potter et al, 2013) included in this review explored a UK population, and this study did not focus solely on women's experiences, but also clinicians' perspectives. Potter et al's (2013) findings were particularly relevant to *The Surgical Consultation* theme developed as part of the review, and expressed views of participants who had chosen all three types of BR. The experience of the surgical consultation involving this UK cohort suggests that restriction of choice may not be uncommon, and justifies further exploration of the decision-making process. In particular, this study and *The Surgical Consultation* theme support further exploration of clinician views, which would be beneficial in understanding breast reconstruction decision-making more clearly.

Overall, there were only four studies that examined the phenomenon in question. The only one of these studies that was based in the UK (Potter et al, 2013) did not explore choice of type of breast reconstruction directly. Two of the studies (Rubin et al, 2013, Boehmer et al, 2007) provided very interesting results that gave further insight into breast reconstruction decision-making (ie *Body Ethics),* however findings were developed from specific groups which may not be transferable to the average UK healthcare context. The last study, although findings were likely transferable, did not provide a significant amount of rich data exploring women's motivations. As findings represented results of a comprehensive search, it is likely that the research question posed is not well answered by the identified studies, particularly in the UK context, and therefore a gap for research exists.

2.6 Conclusion

This chapter describes a qualitative evidence synthesis that contributed to the development of the primary research part of this study described in Chapter 3. A systematic search strategy was employed and yielded rich data, suggesting that a researchable gap remains in the literature. A set of themes were developed from the synthesis of the qualitative evidence. Not all the developed themes were considered transferable to a UK population without further exploration of the particular experiences of women of different cultural backgrounds, and the role played by religious faiths and sexual identities. This review achieved the goal of a qualitative evidence synthesis, established themes that offer rich results, and provided interpretations beyond the original summaries in the included studies.

CHAPTER 3 - METHODS

3.1 Introduction

This chapter provides an overview of the research methods, from initial identification of the research gap, through to the design and implementation of the study. It includes an account of the recruitment strategy, data collection and analysis. The description of the methods will also locate the work in terms of the qualitative approach and philosophical assumptions that underpin the endeavour.

3.2 Study Design and Rationale

As described in Chapter 1, the aim of this study was to answer the research question: *What do women with breast cancer perceive as influential when choosing a type of breast reconstruction?* This question was designed in order to address an area where little is known, specifically exploring the range of factors that influence women's reasoning in their choice to have a particular *type* of reconstruction; in contrast to decisions to have a reconstruction or not, which are widely discussed in the literature (see e.g. Flitcroft et al, 2017). A qualitative approach was chosen to address the research question, as it is more appropriate for exploring the experiences and understandings of those involved in decision-making. The first phase of the study involved recruitment of women who had chosen one of the three major modalities of breast reconstruction, and subsequently interviewing them to elicit what was important to them when they were choosing that type of breast reconstruction. Recruitment occurred across two sites to capture a wider range of women's experiences and care pathways in operation at two different surgical units.

The second phase of the study consisted of interviews with healthcare professionals involved in that decision-making process. Surgeons and breast care nurses involved in the delivery of breast reconstruction services at both study sites were invited to participate in order to explore their experiences of facilitating patient choice. This decision to invite clinicians to be interviewed as well was driven by the literature discussed in Chapter 1 and the findings from the qualitative evidence synthesis described in Chapter 2. Three of the four included studies presented evidence that clinicians influenced choice in various ways, including restricting choice of type of BR (Potter et al, 2013), projecting a personal view of breast reconstruction onto a study participant (Rubin et al, 2013), and failing to engage with study participants' value systems (Boehmer et al, 2007). These findings were reinforced by Flitcroft et al's systematic review (2017) which also made reference to the influence of the surgeon on choice of reconstruction. These findings suggest that a full understanding of the experience of choosing a type of breast reconstruction needed to include an exploration of the views of the clinicians involved in the consultation.

3.3 Qualitative Research

Capturing a rich description of what women saw as influential when choosing a type of breast reconstruction was the primary driver for choosing a qualitative study design. However, exploring decision-making from the clinicians' perspectives and how they conducted, or guided, the reconstructive consultation was a second, complementary aspect of this study. Perception of decision-making is subjective; many factors interact in this complex process that make it difficult to quantify. Consequently, decision-making patterns are typically described qualitatively using terms such as "conceptual models" in the literature (Flynn et al, 2006). Additionally, this study aimed to develop a deeper understanding of a complex decision in health care, therefore a qualitative design is ideal (Pope and Mays, 1995). Qualitative designs are commonly used in the exploration of complex choices, for example, in exploring patient decision-making when seeking GP or emergency care, or when choosing a type of emergency contraception (Henninger et al, 2019, Kaller et al, 2020)

3.3.1 The Qualitative Approach

In choosing one of the overarching qualitative approaches, the most commonly used five approaches to qualitative research were considered, namely: *Narrative Research, Phenomenology*, *Grounded Theory*, *Ethnography* and *Case Study*. Each of these approaches has its own focus and follows its own structure. *Narrative research* focuses on exploring the life of an individual. *Phenomenology* aims to understand the essence of an experience. *Grounded theory* strives to develop a theory grounded in data from the field. *Ethnography* focuses on a description and interpretation of a culture-sharing group. Finally, *Case Study* develops in-depth descriptions and analysis of a case (or multiple cases) (Creswell, 2013). Choice of approach is associated with alignment to specific qualitative techniques or methods.

It has however been recognised that published qualitative work often features mismatches between orientation and technique, or does not claim alignment with any of the five approaches at all (Bradbury-Jones et al, 2017). A *Generic Qualitative Approach* has increasingly been utilised, as an approach *"which is not guided by an explicit or established set of philosophic assumptions in the form of one of the known qualitative methodologies"* (p2; Caelli et al 2003). Generic approaches are flexible, and can borrow techniques and philosophical views from other, established methodologies (Kahlke, 2014; p43). Merriam (1998) mentions that if ethnography concerns itself with culture, and grounded theory attempts to develop theory, then those who employ a generic approach *"simply seek to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved."* (p11).

For this study, a generic qualitative approach as described by Caellie et al (2003), was chosen, on the basis that it was more feasible for a clinical researcher to undertake a rigorous, systematic inquiry without the added requirement of an extensively theory-driven and methodologically sophisticated study design. Researchers must be attentive to the link between the research question, methodology and method, ensuring that the research question informs choices of the latter, instead of the other way around (Kahlke, 2014). The research question of this thesis aims to understand a particular phenomenon (breast reconstruction decision-making) which as per Merriam cited above (1998), is in line with the purpose of a generic approach. Generic approaches are commonly utilised in applied healthcare research, which often focus on pragmatic approaches that can easily translate into clinical practice (Caelli et al 2003, Kahlke, 2014).

The other approaches considered included narrative research and case study; however, they intensively examine individual experiences, or specific cases, as opposed to exploring broader patterns which was the intent of this thesis. Ethnographies focus on culture, typically requiring a deep understanding of cultural anthropology, and would need a significant amount of time to observe participant behaviour which was not feasible for this study (Creswell, 2013). Phenomenological approaches explore the lived experience of a group of individuals, aiming to reduce a common experience into a 'universal essence' (Creswell, 2013; p76). The goal of this thesis was not to reduce informant experience to a common essence, but to encourage varying views and understand different experiences. Lastly, grounded theory approaches were not utilised as their primary aim is to develop theory, which was not in keeping with the aim of this thesis or the research question. Furthermore, the techniques to ensure theoretical sampling was adequate was not viewed as a feasible recruitment process in practice (see section 3.6.1 for further discussion).

Despite its flexible nature, Caelli et al (2003) argue that to be used as a qualitative approach in its own right and ensure credibility, a generic approach must still address the following key tenets: i) the theoretical position taken by the researcher; ii) demonstration of congruence between methodology and methods; iii) strategies used to ensure the research process is rigorous; and iv) the analytic lens used to examine the data is articulated (p5; Caelli et al, 2003). My own theoretical positioning, history and background, which shape the investigation undertaken, was introduced in Chapter 1 (see section 1.1). This has been expanded upon in detail later in this chapter (see section 3.7.1).

The second criterion according to Caelli et al (2003) is congruence of methodology and method. These are distinct as methodology represents the theoretical framework, and beliefs of knowledge and existence that underlie the conduct of the research; the method is the technique(s) used for gathering data and undertaking analysis (Crotty, 1998, Caelli et al 2003). Generic approaches are flexible, and inherently pragmatic. The methodological orientation most suited to this study, which was also congruent with this approach, was pragmatism. It is commonly associated with both quantitative and qualitative approaches, particularly when combined, and "is not committed to any one system of philosophy or reality" (Creswell, 2013; p28). This study employed an interpretive framework in acknowledgement that the subjective realities of informants are formed through (social) interaction with others, and should take into account complex viewpoints shaped by the histories and cultural backgrounds of both the participants and the researcher. To achieve this, methods such as interviewing, observation and/or textural analysis of artefacts can be employed (Creswell, 2013). As the aim of this study was to develop an understanding of the decision-making phenomenon from the perspectives of women and clinicians involved, semi-structured interviews were chosen as the best method to capture subjective accounts (Britten, 1995).

The chosen method for analysis was thematic analysis (Braun and Clarke 2006). This technique is a flexible approach which is not in itself wedded to any specific underlying qualitative approach, theory or epistemology (Braun and Clarke, 2006). Using this technique allows themes to be developed that describe patterns across the dataset; it is also the method most commonly associated with a generic qualitative approach (Bradbury-Jones et al, 2017). The mechanics of how thematic analysis was used in this study are discussed in depth further in this chapter (see section 3.8.1). Likewise, the choice of design, made to ensure rigour, and the approach for ensuring transparency are described later in this chapter (see section 3.10).

As outlined above, the analytical lens applied was also that of pragmatism, predicated on the idea that ‘reality is what is useful, is practical, and “works”’ (Creswell, 2013, p37) and that ‘reality is known through using many tools of research that reflect both deductive and inductive evidence’ (Creswell, 2013, p37). Again, this is congruent with a generic approach adopted for the study.

3.3.2 Approach to Data Collection

There are four major types of qualitative data collection: observation, interviews, documents and audio-visual materials (Creswell, 2013). A generic qualitative approach can be associated with any of these types apart from observational studies (Bradbury-Jones et al, 2017). Observing a consultation where reconstruction was discussed, whilst providing potentially valuable context, would not elucidate women’s views and perceptions of the decision-making process unless they surfaced through interaction between surgeon and patient. Observational data is more typically associated with case study, grounded theory, ethnography and phenomenological approaches (Bradbury-Jones et al, 2017). Use of documents and audio-visual materials was not appropriate for this study. Use of a qualitative surveys (open questions for free text responses) was considered for data collection as they can be useful in obtaining responses from a large sample. However, the pre-determined, fixed nature of surveys reduces flexibility, and therefore opportunity to explore a topic about which little is known, which was the key driver of this research.

Both individual interviews and focus groups were considered. Convening a focus group has multiple advantages. Discussions between group participants can reveal dimensions of understanding that can provide more depth than traditional individual interviews, and a larger group of people can be interviewed quickly (Kitzinger 1994). Disclosure of sensitive issues and painful experiences may be easier for some women, when reassured by the presence of other women with a similar experience.

The disadvantages of focus groups however discouraged choice of this method of data collection for this study. Experience of moderation is required to manage a focus group (Kitzinger 1994). For example, keeping the conversation to a specific topic may have proved difficult without experience (Braun and Clarke, 2013). As this study was my first experience of qualitative data collection, undertaking pilot focus groups to gain experience may have even been ethically unsound. Also, an in-depth examination of any one group member's experience may have proved difficult. This was necessary as I predicted that I would require the flexibility to go beyond simply finding out why women want reconstruction, which is already well documented (see e.g. Flitcroft et al, 2017), and delineate their views on particular types of reconstruction. Lastly, sometimes in groups, women may be reluctant to go against group consensus, or discuss certain topic areas, which they may have divulged if in private (Kitzinger, 1994).

Semi-structured interviews were therefore chosen as the ideal method for collecting data for this study. They are best suited to researching questions related to experience and perception, particularly when participants have a personal stake in the matter (Braun and Clark 2013). This research focuses on exploring what women felt influenced choice of type of breast reconstruction, which lent itself to an in-depth examination of the experience, that was best achieved through a *'conversation with a purpose'* (Burgess, 1984; p102). The qualitative studies identified in the thematic synthesis in Chapter 2 also used individual interviews, which contributed to this choice. Another factor that contributed to the decision to undertake an individual interview-based approach was the flexibility they afforded to respond to unplanned avenues of questioning, and allow sensitive issues (which in this case was relevant given discussion of the breast and cancer) to be discussed with privacy (Kvale, 1994, Braun and Clarke, 2013). These benefits outweighed the limitations of an interview-based approach to data collection, including smaller sample sizes (than focus groups) and the time-consuming nature of interviews (for the researcher and participant) (Braun and Clarke, 2013). There are different types of individual interviews. Open-ended/narrative interviews do present an advantage in the exploration of patient journey. Semi-structured interviews however are the most commonly utilised method of data collection in qualitative research, including healthcare (Kallio et al 2016). They offer a focused structure for discussion (in order to address specifics of a research question), and also allow versatility and flexibility in improvised follow-up questions, which can encourage unique responses from informants (Kallio et al 2016).

3.4 Ethical approval

Sponsorship was provided by the Research and Development (R&D) Department of Site 1. The initial protocol and supporting documentation were reviewed by clinicians who supported the initial development of the study (MS/GS) and both qualitative supervisors of the research team (AL/GC – see section 3.7.1.1), before being reviewed by the Head of Research and Development at Site 1. These documents were submitted via IRAS and ethical approval was granted by the Derby (East Midlands) Research Ethics Committee (REC), after a single face-to-face meeting with the committee (REC reference 15/EM/0488). Few amendments were required, primarily the requirement for provision of a local lone worker policy, and changing the wording of some of the supporting documents. The complete favourable opinion from the REC was given in January 2016. To increase the rate of successful recruitment, a substantial amendment was submitted to the same REC, and granted in February 2017. This amendment will be discussed later in this chapter (see section 3.6).

3.4.1 Ethical considerations

Minimising risk of harm is core to ethical practice in research. For participants who had traumatic experiences of breast cancer, including mastectomy and reconstruction, this study presented some risk. Re-living this experience was discussed during the panel review with the East Midlands REC. The steps in place to minimise harm were clearly explained. All participants could stop the interview at any point if they were distressed or experiencing discomfort, and it was not required that they answer each question. I also checked that all women had the details of their 'named breast care nurse' in case they felt they required support dealing with the experience, within office hours. They were also directed towards 24-hour support services such as Samaritans, 111 and even 999 in case of severe distress out of office hours. There was no financial remuneration or reimbursement provided to participants.

3.5 Overview of Study Sites

Recruitment occurred over two sites in order to explore whether decisions could be influenced by the characteristics of the site. Both hospitals were district general hospitals, however Site 1 was in a major UK city, and had its own plastic surgery unit that specialised in breast reconstruction. Site 1 therefore offered a full range of breast reconstruction procedures, including DIEPs, LDs and implant-based reconstruction. Site 2, which was located in a smaller city, did not have an in-house plastic surgery unit, but the oncoplastic surgeons provided IBR as well as LDs. They however had an agreement with a private hospital in a nearby city, allowing for referral of patients that were suitable for DIEP. Table 1 below summarises key features of both sites.

Table 3. 1 – Site Characteristics

	Site 1	**Site 2**
Location	Major UK city	Smaller UK city nearby Site 1
Oncoplastic Breast Surgeons	1 (newly appointed)	4
Plastic Surgeons	Initially 2, reduced to 1 during the study	None
Autologous Procedures	LDs and DIEPs performed in-house	LDs performed in-house. DIEPs referred to a private hospital in same city as Site 1

3.6 Participant Recruitment

This section discusses the recruitment method utilised in this study both for women who had a breast reconstruction and clinical staff. Care is taken to refer to the patients recruited to this study as women, recognising that they are not defined by their illness. Sampling in qualitative research is typically *purposive* in nature - cases are selected to provide rich data for analysis (Bradbury-Jones et al, 2017, Patton, 1990). Some argue this term is ambiguous and often inadequately describes how participants were recruited. Palinkas et al (2015, p533) define purposive sampling as *"identification and selection of information-rich cases related to the phenomenon of interest"*. It is a non-probability type of sampling that is commonly associated with qualitative research and generic qualitative approaches. At the time of study design, a purposive sampling strategy was developed, with the initial aim of recruiting 6-8 patients from each site, for each reconstructive modality, and to recruit 4-8 patients across both sites who had declined reconstruction; this would have amounted to a total of 40-56 patients across both sites. The inclusion and exclusion criteria for the purposive sampling strategy are described in Table 3.2 below, at the end of this section. The use of purposive sampling was thought to be best for ensuring variability and information-rich interviews, by identifying women of different ages, ethnicity and reconstruction timing (delayed versus immediate). If initial analysis produced themes that warranted further interrogation, it was planned to use theoretical sampling (a process whereby analysis and development of theory guides subsequent participant selection in order to explore new themes (Coyne, 1997)) which is often associated with grounded theory approaches. The originally planned sampling strategy proved over ambitious. In the end, a more pragmatic purposive sampling strategy, consecutive criterion sampling, was employed. Delays in recruitment requiring change in the sampling strategy are described later in this section and in the next section (see section 3.6.1).

As this study sought to explore all aspects of the breast reconstruction consultation and decision making, and given that the breast reconstruction offer was variable in different cancer networks (Jeevan et al, 2014), it was decided that women who had declined reconstruction were also suitable for recruitment. Their experiences were thought to be important in understanding how breast reconstruction was offered, and what aspects of each type of breast reconstruction could have motivated a woman to reject reconstruction altogether. However, it was not intended to recruit women who had simple mastectomy, but awaited a delayed reconstruction. The primary reason was to prevent any influence on the decision-making process. This was recommended by the Research Ethics Committee, as they expressed ethical concerns that involvement in a voluntary research study could result in the change in reconstructive choice of a participant, and ultimately could end up having a procedure she did not want. Likewise, a post-operative interview was chosen (as opposed to pre-operative interview) to remove the possibility of the researcher and the interview itself providing a space to rehearse selection and influence choice of type of reconstruction.

Identification of study participants and arrangement of interview

Identification of study participants was initially through post-operative breast reconstruction clinics. To avoid unnecessary visits to the hospital, it was decided that potential participants could be approached if they were already booked to attend for a post-operative appointment. The study information sheet was mailed to the potential participant one week prior to the four-six month routine post-operative assessment, along with a consultant letter that endorsed the study. The information sheet highlighted that the potential participant would be approached by the researcher after their consultation with their surgeon. If she had already received and read the recruitment pack she was shown to a clinic room, in which the study was discussed and questions about participation answered. If the woman was happy to proceed, the consent form was explained and signed. The consent form highlighted the fact that all personal details would remain confidential within the research team and the University of Birmingham, and stated that any data suitable for publication would be appropriately anonymised to protect confidentiality.

The interview date and time were then arranged at least seven days after consenting (to provide a cooling off period), but ideally within 14 days (so that the date would not be forgotten). The contact details form was filled in, containing a tear-away slip with the interview date and time recorded, for the participant to keep. This slip would also have the details of a named breast care nurse, to whom they could speak in case of emotional/psychological distress following the interview. Participants were given the option of face-to-face or telephone interviews. If a telephone interview was preferable, then their preferred contact telephone number was also taken down on the contact details form. Participants opting for face-to-face interviews were offered either an interview at their home or a clinic room in their hospital. The four-six month post-operative window was chosen as it was thought that any sooner could be stressful for the participant, or that they may not have time to fit it in given their recovery requirements. Any delay longer than six months could increase the risk of recall bias.

This initial recruitment strategy was strict and recruitment was slow. The four to six month post-operative window, coupled with only being able to recruit through the consultant outpatient clinic both contributed to this. Some potential participants were seen in clinic just before four months, and given a three-month follow-up, and therefore were outside the recruitment window. If the potential participant was seen in clinic within a four to six month time window, but I was on-call or on annual leave, then the opportunity to successfully recruit was lost. Furthermore, if the participant had not had a chance to read the recruitment pack before the post-operative clinic, recruitment could not occur. The protocol did not allow for immediate consenting, as the participant would not have had time to consider the study, irrespective of the cooling off period that was required for all those who consented. The two primary issues which contributed to the decision to seek a protocol amendment were the duration of the recruitment window, and that recruitment could only occur at the post-operative clinic.

Another issue that became apparent was the proposed sample size. Despite the difficulties that emerged related to recruitment, the first five interviews elicited rich and complex data. The interviews lasted on average 74 minutes, which was not originally expected. This was discussed within the research team (AL/GC – see section 3.7.1.1). It was agreed that if this quality of interview were to continue, the initial proposal of 40-56 interviews would be beyond the scope of a qualitative doctoral thesis, in terms of size. Performing this number of interviews was also possibly inappropriate, as sample size adequacy ("saturation") is usually achieved with smaller numbers (see section 3.6.1 for further discussion and explanation). The decision was made within the research team (AL/GC) that fewer interviews would probably produce the rich data required and therefore a total of 20 participant interviews (ten at each site) became the target for recruitment. This was also included in the protocol amendment.

The substantial amendment to the protocol was submitted and approved by the Derby, East Midlands REC. The amendment allowed for ongoing recruitment at any time within six months of the procedure using the existing method. However, it also allowed women who met the inclusion criteria (and therefore were pre-screened), but had no four-six-month post-operative clinic appointment, to be recruited. They would be mailed a recruitment pack, which included a consent form with an envelope, and prepaid postage stamp. They would then be telephoned one week later to discuss participation in the study. If they had had time to go through the documentation, then any questions could be answered, and the consent form could be signed whilst the researcher was on the telephone. The potential participant would then mail the consent form to their hospital, and an interview date would be set up, again either face-to-face or over the telephone. By whichever method the participant was recruited, it was still the aim that the interview itself would still occur within the four-six month postoperative window. This amendment to the recruitment strategy along with a change in the sample size allowed for successful recruitment of ten participants at each site. Notably, interview quality did not decline and was similar to the first five interviews. The first ten interviews were completed at Site 1 before Site Specific Approval was obtained at Site 2. A preliminary coding framework was developed based on the first five interviews. This framework assisted in the analysis of the remaining interviews, and adequacy of sample size (or "saturation") was thought to have been achieved around interview 13, as few new codes were developed following this (see section 3.6.1 for further discussion and explanation).

Table 3. 2 – Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Adult female of at least 18 years of age	Breast reconstruction not for breast cancer, carcinoma-in-situ, or risk-reducing for breast cancer
Patient having had immediate or delayed breast reconstruction	
Able to give informed consent for post-operative interview	
Fluent in the English language	
Can be interviewed in the 4-6 month post-operative window	

3.6.1 Discussion of Recruitment - Women

After optimising recruitment through the protocol amendment, the first ten women who met the inclusion criteria at each site, and who agreed to participate, were recruited. The initial purposive sampling strategy aimed for a variation of age, ethnicity, type of reconstruction, timing of reconstruction, geographic location, and also aimed to include those who declined reconstruction. This could be described as a type of purposive sampling known as maximum variation sampling (Creswell, 2013). The change in sampling strategy requires reflection. Convenience sampling suggests that participants meet practical criteria (Patton, 1990), such as availability at a certain time for interview, easy accessibility, willingness to participate and proximity for interview. Its lack of strategic purpose is thought to reduce credibility (Creswell, 2013). The approach I have utilised may draw comparison to convenience sampling due to the accessibility of the women recruited, but these women were not chosen without strategy or purpose. They were only approached for participation if they met reasonably strict inclusion criteria. I suggest that the approach that was eventually employed could be described as a variation of purposive sampling, that I have termed consecutive criterion sampling. Criterion sampling is a common form of purposeful sampling that often occurs in phenomenology, in which participants who have shared a common experience, or meet a particular criterion, are sampled (Creswell, 2013). Despite the consecutive nature of this approach, the overall desired variation of the target phenomenon was achieved (see section 4.2 for summary of participant characteristics), which matched the objective of this study.

The eventual sample did also deviate from the original plan as it proved difficult to recruit women who had declined reconstruction. There was only one participant from Site 1 and it transpired that even this participant aimed for delayed reconstruction sometime in the future, which she did not disclose at the time of recruitment. These women would not typically present to the reconstruction clinic, so the breast care nurses (BCNs) at the different sites were asked if they could identify participants who declined reconstruction. This represents an attempt at snowball sampling, in which cases of interest are identified by “people who know people” (Creswell, 2013; p158). Unfortunately, I was unable to recruit any of these women.

The proposed sample size of a study should also be in keeping with the chosen qualitative approach (Sandelowski, 1995). A generic qualitative approach tends towards a sample size of 12 to 15 participants (Bradbury-Jones, 2017), although most studies report between 15 and 30 individual interviews, to be considered adequate for generation of patterns in the data (Braun and Clarke, 2013). Too small a sample size may limit the ability of a study to generate new and rich meanings of experiences, whilst too large a sample size may detract from deep, case orientated analysis (Sandelowski, 1995). As previously, a sample size of 20 women was agreed upon. This was in keeping with the framework of pragmatism, as techniques can be adapted as benefits the researcher and the study.

‘Adequacy’ of the sample size can be difficult to describe, and in fact is also dependent on the chosen qualitative methodological approach (Vasileiou et al, 2018). Various terms have been used to describe this, including informational redundancy, information power, and most notably, saturation (Vasileiou et al, 2018). Saturation is a principle that determines sample size sufficiency in qualitative research, and is most frequently associated with a grounded theory methodological approach (Glaser and Strauss, 1967, Strauss and Corbin, 1998), which was not utilised in this study. In grounded theory approaches, sample size is viewed as adequate once theoretical saturation of data has occurred, which has been described as: "*i) no new or relevant data seem to emerge from a category, ii) the category is well developed in terms of its properties and dimensions demonstrating variation, and iii) the relationships among categories are well established and validated*" (Strauss and Corbin, 1998; p212). Nonetheless, all these terms equate to varying concepts of sample size sufficiency. These terms can suggest 'no new data', 'no new themes', 'no new codes', and in theoretical saturation as above, 'no new theoretical insights' (Vasileiou et al, 2018). It is not always possible to determine the sample size at which saturation occurs a priori, however it is thought to usually occur at the point of 12 interviews (Guest et al, 2006). The adequacy of the sample size in this study implies the point at which no new codes were developed.

3.6.2 Participant Recruitment – Clinicians

The original aim was to recruit any clinicians involved in reconstructive surgery at either site who were willing to participate. It was intended that the study would recruit at least two plastic surgeons, two oncoplastic breast surgeons, two breast surgeons not performing reconstructive work, and two breast care nurses (in total, eight clinicians across both sites). Unfortunately, time constraints and limited responses to invitations resulted in recruitment of one plastic surgeon (from Site 1), three oncoplastic surgeons (one from Site 1, two from Site 2) and two breast care nurses (both from Site 1). Therefore, this phase of the study represented convenience sampling. Potential study candidates were sent personal emails using the confidential nhs.net mail service, inviting participation, with an attached information sheet. The consultants and breast care nurses that responded to the invitation were all known to the researcher. Written consent was either taken at the time of interview or in advance of the interview. Participants were offered either telephone or face-to-face interview.

3.7 Data Collection

This section discusses data collection techniques used in this study.

3.7.1 Reflection on Researcher Characteristics

Data do not simply emerge, but rather the researcher must actively identify patterns of interest which he or she thinks would be of interest to the reader, and represent the interpretations generated through the analysis process (Thorne, 2000). Data are selected, codified and edited in response to the research question, in this case through my endeavours, under the supervision of the qualitative experts of the research team (initially AL/GC, later AL/AT – see section 3.7.1.1). Consequently, the background of the researcher must be openly discussed so the reader can judge the veracity of the research processes employed and may take these into account when assessing the account of the research.

I conducted all the interviews that are reported in this thesis, in order to submit for the award of Doctor of Medicine (MD). I was a 28-year old male at the time of commencement of data collection (29 by time of completion) and of Canadian nationality (but Sri Lankan ethnic background). I rapidly recognised that my research question required a qualitative approach. I had no training in qualitative research prior to beginning this study, however I completed the Qualitative Research Methods module at the University of Birmingham and continued to learn along the way through reading and guidance from supervisors.

Before taking time out of training to conduct this research, I worked in the breast reconstruction unit at Site 1 as a Foundation Year doctor. As such, I had some knowledge of breast reconstruction procedures and an understanding of the breast reconstruction pathway, which allowed for informed discussion with both women and clinicians. Due to my work experience, I knew several clinicians involved in the study.

The starting point for this research, which inspired my interest in the undertaking of this study, including formulation of the research question, was from the perspective of a junior doctor working in a breast reconstruction unit during Foundation Year training. When setting out any pre-existing assumptions about the topic, they may have been framed by my clinical background, and influenced by the training I received at a site that frequently performed autologous reconstruction. I do not have any friends or family with experience of breast reconstruction. I should also recognise the change in myself throughout the undertaking of this work, as I entered and completed training as a general practitioner (GP) in the UK, after completing the data collection phase. I continued to analyse data and write up my thesis whilst in training, and following training as well. My views have perhaps changed from that of an aspiring surgeon to those of a GP, which increasingly focuses upon holistic, but complex patient-centred care. Through this journey I have since come to recognise that I am undoubtedly shaped by my professional socialisation, gender, culture, status/position, and that will have influenced all aspects of this endeavour. However, I have sought to adopt a reflexive stance, demonstrate transparency in the actions taken in the conduct of this study, and offer interpretations and analysis based on theoretical notions that were driven by the data produced.

There were potential limitations given my characteristics. Firstly, I am a (relatively) young male. As the focus of this study could be described as sensitive, I recognised that that I have different demographic characteristics from my target group of informants, so all women were offered the option of telephone versus face-to-face interviews. Despite the disadvantage of loss of non-verbal data, telephone interviews are thought to be able to provide rich data, allow interviewees to remain in their own comfort-zone, maintain anonymity and privacy, and decrease social pressure (Novick, 2008). It was thought that some participants might prefer a telephone interview due to the differences in demographic characteristics, whereas others would prefer the warmth and potential for increased rapport in a face-to-face interview. It was initially planned that if the data from telephone interviews appeared to lack richness compared with data collected from the face-to-face interviews, then face-to-face interviews would be made a priority. This problem was not encountered in this study; this may be a result of the training in communication skills I received as a core component of medical training in the UK.

Participants were aware that I was a medical doctor. This decision was discussed during supervision, as it can make some participants feel more comfortable discussing both complex and personal experiences. However, it is also possible that participants may not be so forthcoming, in fear of making incorrect medical statements. It has been reported that participant knowledge of the interviewer being a doctor can influence interview content, for example deference to, and social alignment with the doctor, in working-class and middle-class respondents, respectively (Richards and Emslie, 2000). Furthermore, there was the risk that participants may ask for medical advice or opinions; however, this was only encountered in one interview. The participant was advised that medical opinions could not be offered, and she was directed to her breast care nurse, for whom she had the relevant contact details. I also emailed the participant's breast care nurse, suggesting she check-in with the participant via telephone. The richness and complexity of the data collected from the majority of the other interviews did not suggest any discomfort experienced by the women recruited. Clinician interviews also seemed rich, and thick data was collected. It may be that my pre-existing relationship encouraged open, authentic conversations, as some clinicians felt able to disclose their preference for specific reconstructive modalities.

3.7.1.1 The Research Team

As I have introduced myself, it is also worth introducing and explaining the structure of the research team. At the outset of the study, two clinicians supported the development of the study design, MS (breast surgeon) and GS (plastic surgeon). Two qualitative research experts formed the research team along with myself, AL (Lecturer in Medical Sociology and Qualitative Methods) and GC (Qualitative Research Specialist – Chronic Disease). In October 2019, the research team changed, and AT (Professor of Nursing) replaced GC (due to unanticipated personal reasons).

3.7.2 Interview Schedule

The interview schedules were guided by the qualitative evidence synthesis conducted and reported in Chapter 2, as well as the clinicians (MS/GS) who supported the preparation of the study. The qualitative evidence synthesis suggested many influential factors. Addressing them individually in the topic guide was not ideal (see section 3.7.3 below), however broad questions were thought to organically prompt the factors women found influential. The patient interview schedule consisted of open-ended questions that focused on varying aspects of the breast reconstruction journey, including diagnosis of breast cancer, the process of choosing a type of breast reconstruction, sources of information, and satisfaction with the reconstruction (please see Appendix 2). The women recruited were made aware that they could decline to answer a question without having to give a reason.

The clinician interview schedule (please see Appendix 3) explored the clinician's opinion of the same questions asked to the women, but also explored their surgical unit and operative repertoire. It was developed to be applicable to both the breast care nurses and consultants. The schedules were piloted with another qualitative researcher prior to interviewing; feedback was positive, with no significant changes required. There was consideration of including the first interview with a woman as a pilot as well, however the data collected were so rich that the decision was made within the research team (AL/GC) to include this as part of the study.

3.7.3 Data Collection - Women

At the time of interview, a signed consent form was either with the researcher or in the Site File of the relevant site. Consent for study participation was re-confirmed at the beginning of the interview, and it was reiterated that they were under no obligation to complete the interview. The contact details of a 'named breast care nurse' were also discussed. Consent to audio-record the interview was obtained as well. The interviews largely followed the semi structured interview schedule, but participants were encouraged to express whatever it was they felt was important about their decision-making, and the care they had experienced.

Two amendments were made to the interview schedule. The first addressed the way in which possible factors influencing choice were posed to participants. Perhaps not appropriate for a semi-structured interview topic guide, possible factors were initially listed, for discussion of any role they might have played in the decision-making process. It was decided within the research team (AL/GC) that this should be changed as a participant may agree to the suggestion that a particular factor was important, or may not remember, and feel that such a factor was sensible, as opposed to having had experienced this in reality. This part of the interview schedule was changed from the fourth interview, and instead women were asked if they could list, in order, the most influential factors in their decision-making process. For women who had difficulty answering the questions, some factors noted in the qualitative evidence synthesis could be used as prompts. The second addition was a question regarding the participant's thoughts on the breast reconstruction support group. This was only available at Site 1, and not at Site 2. The first three participant interviews appeared to value this group, and given that it was available at only one site, it was thought to be useful to explore if it had any impact on decision-making for the women.

3.7.4 Data Collection – Clinicians

Similar to the women recruited to this study, written consent was obtained before all interviews, with ongoing willingness to participate confirmed again at the time of the interview. Consent was taken to audio-record the interview as well. It was reaffirmed that all personal details would remain confidential to the University of Birmingham research team, and that any data included in reports and publications would be anonymised to protect confidentiality. Importantly, clinicians were advised as part of the consent process, as required by the REC, that disclosures of malpractice would need to be reported. Also similar to the first phase of this study, I stated that the interview could be ended at any time, that not all questions needed to be answered, and that there was no need to provide a reason for not answering a question. Participants were free to withdraw if they so desired, but none opted to do so. Due to women's interest in the patient-led support group, questions regarding this as an emergent theme were added to the interview schedule for clinicians.

3.8 Data analysis

Interview recordings were transcribed verbatim. Recordings were sent to and returned securely from a research support company specialising in transcription. It was both a frequently used and trusted service, utilised by the University of Birmingham, with robust confidentiality and information governance policies in place. Upon receipt of transcripts, and anonymisation of all identifiable information, I independently coded each transcript after several iterations of transcript review. Each transcript with relevant coding was then reviewed and discussed within the research team (AL/GC) until there was overarching agreement. Coding was initially performed using NVivo version 10, which is a software programme to aid qualitative data analysis. The software allowed for capture and generation of a set of codes which were reviewed within the research team (AL/GC) to develop a preliminary coding framework, across the first five women from Site 1. This framework was used to guide the subsequent coding from the remaining women from Site 1 and the ten participants from Site 2.

I also independently coded each of the clinician transcripts after several iterations of transcript review. Similarly, each transcript with relevant coding was then reviewed and discussed within the research team (AL/GC) until there was overarching agreement. Initially, the codes were analysed using the same framework as the women. It was however agreed upon review (later, with AL/AT) that use of the same framework was not reflective of the many differences between patients and clinicians. The previously developed codes were subsequently reworked separately from the women's codes in March 2021, as described in section 3.8.1 below.

3.8.1 Thematic Analysis

The chosen theoretical framework and method of analysis (as described in section 3.3.1) should match the research question, and the decisions made during the research process made clear. Thematic analysis (Braun and Clarke 2006) was chosen as a method for qualitative analysis, as it is a highly flexible technique that can be applied across a wide range of theoretical and epistemological approaches (Nowell et al, 2017). Thematic analysis can be described as a method for identifying, analysing, and reporting patterns, or themes, within the data (Braun and Clarke 2006). Similar to other methods of analysis, this is undertaken across an entire data set (as opposed to individual interviews), however it is not bound to the implicit theoretical commitments of a 'named' type of analysis (Nowell et al, 2017). As this study presents an applied healthcare oriented thesis written for submission of the award of Doctor of Medicine, thematic analysis therefore allowed the researcher to focus on conducting a rigorous and systematic qualitative analysis without the added requirement of an extensively theory-driven and methodologically sophisticated study.

Development of themes occurred by identification of patterned responses found within the data set. These patterns provided an answer or relevant information regarding the research question. Although development can be influenced by frequency of appearance, themes were actually developed based on how well they related to the research question, assessing for relevance rather than prevalence (Braun and Clarke, 2006). I followed an inductive approach to provide a descriptive account of the data. The six phases of thematic analysis as per Braun and Clarke (2006), were used to structure the analysis in a recursive process. Analysis began by immersion in the transcripts (Phase 1). Time constraints did not allow for me to transcribe, however as I performed all the interviews myself, and kept detailed field notes, immersion in the data was felt to be achieved by repeated reading. Codes were developed into higher level codes (Phase 2), which were organised and mapped into subthemes and themes (Phase 3) by the original research team (AL/GC). Subthemes and themes represented factors that influenced choice of type of reconstruction, or were important when choosing reconstruction. A second round of analysis took place from December 2020 with the new research team (AL/AT). The previously developed, extensive list of subthemes and themes went through multiple iterations of analysis (Phase 4). Themes and subthemes were developed, and collapsed, or broken down, requiring return to transcripts to ensure themes accurately reflected the data. Eventually they were reduced to three themes (Phase 5 – named in section 4.5), representing influences of breast reconstruction choice. These are explored in Chapter 4 (see section 4.5), presenting compelling extracts from women (Phase 6).

The clinician transcripts were analysed using the same approach and analytical technique described above. Subthemes and themes were mapped from higher level codes (developed within the original research team, AL/GC) in 2019. This was revisited by the new research team (AL/AT) in February 2021 agreeing upon re-analysis independent of women's interviews. I revisited the codes and higher level codes previously developed, and then re-analysed the subthemes and themes discussed within the current research team (AL/AT). The number of overarching themes was also reduced to three. These are explored in Chapter 5 (see section 5.3).

3.9 Reflexivity as part of the analysis

Reflexive journals are used to document researcher subjectivity throughout a qualitative study, in order to enhance credibility. Continuous introspection and reflexivity acknowledges the way the researcher interacts with the research and the informants, and is important in ensuring rigour (Bradbury-Jones 2007). In this study, a reflexive journal was kept throughout the data collection and analysis stage. The most important disclosure that must be made is the shift in my subjectivity, which was initially perhaps more clinical or doctor-centric in views of women's decision-making. For example, I had noted slight criticism of the way complications had been interpreted, or in the way decisions had been handled. There was also a slight inward preference of autologous reconstruction over IBR, likely due to my training experience, which actually shifted throughout my journey with this research. As I progressed through and completed GP training, with age and experience, I had become much more accepting and measured, which I noted in myself upon re-reading the same transcripts. I think there may have been a shift as well, from possibly a more 'black and white' world view when I aspired to be a surgeon, to a view that acknowledged all the greys in between. Being reflexive of these views, and of the factors that shaped and influenced me (see section 3.7.1) throughout this process, helped me maintain objectivity as best possible, whilst writing this work.

The reflexive journal was also used in a practical sense, to keep field notes, to support decision making throughout the project, and to monitor the richness of interviews, for example by keeping a close eye on the quality of telephone interviews. If richness was lacking, I could have prioritised face-to-face interviews. I also used the reflexive journal to underpin adaptations in the interview schedule, for example to note if a different opening question was found to be more effective, or potential themes that emerged from the interview.

3.10 Rigour

Rigour in the conduct of a study underpins the trustworthiness of the results. The criteria for rigour in a qualitative study are often given analogues to those found in a quantitative study. In a qualitative study, internal validity can be called *credibility*, external validity can be called *transferability*, reliability can be called *dependability*, and confirmability can be called *neutrality* (Schwandt, Lincoln and Guba, 2007). Rigour is in fact a theoretical issue, as opposed to a technical one, and is frequently overlooked in generic approaches (Caelli et al, 2003). Nonetheless, as outlined earlier in this chapter, Caelli et al (2003) suggest that qualitative researchers articulate a theoretically informed choice to rigour and ensure that said approach is congruent with the philosophy and methodology of the inquiry. Some techniques for establishing rigour, for example member checking (when participants review their own interview transcripts), are bound to certain theoretical frameworks (Birt et al, 2016). The pragmatic interpretive framework chosen however is an atheoretical approach, not wed to a specific philosophy or methodology. Consequently, any practical approach to rigour could be adopted for this study.

I was informed by Nowell et al's (2017) guide to meeting 'trustworthiness' criteria in thematic analysis approaches, primarily because it was specific to thematic analysis, it was explicit in its recommendations, and it was frequently cited. The six phases of Braun and Clarke's thematic analysis (2006) have been identified earlier (see section 3.8.1), and Nowell et al's guide (2017) follows these phases, attempting to link back to Lincoln and Guba's descriptions of credibility, transferability, dependability and confirmability. With pragmatism in mind, Nowell et al's approach (2017) was followed as a guide, not prescriptively.

i) *Familiarisation*. It is suggested that immersion in the data, with multiple iterations of review of the data, and reflexive journaling support rigour. Both were employed in this study.

ii) *Coding*. Credibility is suggested by data analysis by more than one researcher. All coding was reviewed for agreement within the original research team (AL/GC).

iii) *Searching for Themes*. Confirmability is proposed by keeping detailed notes about the development of subthemes/themes, which was evident in meeting notes from initial team meetings (AL/GC).

iv) *Reviewing Themes*. Themes should be grounded in the data. Team review (AL/AT) of coded data extracts and return to review raw data (DL) occurred for all subthemes/themes to ensure that they represented the participants' accounts.

v) *Defining Themes*. Consideration of what each theme captures, and how each theme fits into the overall story of the entire data set. Again this was done primarily through team review (AL/AT), with evidence in meeting notes. Ordering of themes occurred until consensus was achieved.

vi) *Producing the Report.* Validity is suggested by presentation of extracts of raw data within an analytic narrative, which illustrate a complex story and go beyond simple description. These are presented in the Chapters 4 and 5. Analytic credibility depends on the coherence of the argument, and locating results in the literature – this is presented in Chapter 6. Ensuring transparency in the methods can be done via the COREQ checklist.

Overall, rigour was maintained through each step of the analysis process, primarily through review within the team, reflexivity and note keeping. To ensure transparency in the methods, the COREQ reporting guideline was utilised, as per Nowell et al's recommendation.

The COREQ checklist is a 32 item criteria for reporting qualitative research (Tong et al, 2007). It was developed to guide consistent and explicit reporting of qualitative data, similar to guidelines developed to improve the quality of reporting of randomised control trials (ie CONSORT statement – Altman et al, 2001). It consists of three domains: i) research team and reflexivity, ii) study design and iii) analysis and findings. Care must be taken when assessing the quality of a study based on the COREQ checklist. There is some debate within the literature, suggesting that checklists such as COREQ can be falsely reassuring, for example if "simple [implying without rich data] research is not appropriately challenged because of standardised ways of reporting research" (Buus and Agdal 2013; p 1290). Part of this reasoning includes the content of the checklist. Consider item 22 in Table 3.4 below. Saturation (see section 3.6.1) is a measure of sample size adequacy most frequently associated with a grounded theory approach. It would not be methodologically sound for another, theoretically bound approach to utilise saturation. Also consider item 23 in Table 3.4 below. Return of transcripts for checking (member checking) is again a method of ensuring rigour, that is bound to particular theoretical frameworks (Birt et al, 2016). Despite its flaws, it is a frequently utilised reporting tool, supported by major journals (ie the British Medical Journal (Buus and Perron, 2019)) and explicit in its recommendations. Therefore, the COREQ checklist is presented in Tables 3.3, 3.4 and 3.5 below. It is presented as a guide to transparency, as opposed to a prescriptive exercise or an assessment of the quality of this thesis.

Table 3. 3 – COREQ Checklist Domain 1 (Tong et al, 2007)

	Item	Description	Section
Domain 1: Research team and reflexivity			
Personal characteristics			
1	Interviewer/facilitator	Which author/s conducted the interview?	3.7.1
2	Credentials	What were the researcher's credentials?	3.7.1
3	Occupation	What was their occupation at the time of the study?	3.7.1
4	Gender	Was the researcher male or female?	3.7.1
5	Experience and training	What experience or training did the researcher have?	3.7.1
Relationship with participants			
6	Relationship established	Was a relationship established prior to study commencement?	No
7	Participant knowledge of the interviewer	What did the participants know about the researcher?	3.7.1
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	3.7.1

Table 3. 4 – COREQ Checklist Domain 2 (Tong et al, 2007)

	Item	Description	Section
Domain 2: Study design			
Theoretical Framework			
9	Methodological orientation and theory	What methodological orientation was stated to underpin the study?	3.3.1
Participant selection			
10	Sampling	How were participants selected?	3.6/3.6.1
11	Method of approach	How were participants approached? Se	3.6
12	Sample size	How many participants were in the study?	3.6
13	Non-participation	How many people refused to participate or dropped out?	None
Setting			
14	Setting of data collection	Where was the data collected?	3.6
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16	Description of sample	What are the important characteristics of the sample?	3.6
Data Collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it piloted	3.7.1
18	Repeat interviews	Were repeat interviews carried out?	No
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	3.7.2
20	Field notes	Were field notes made during and/or after the interview or focus group	3.9

21	Duration	What was the duration of the interviews or focus group?	3.6
22	Data saturation	Was data saturation discussed?	3.6/3.6.1
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction	No

Table 3. 5 – COREQ Checklist Domain 3 (Tong et al, 2007)

	Item	Description	Section
Domain 3: analysis and findings			
Data analysis			
24	Number of data coders	How many data coders coded the data?	3.8
25	Description of the coding tree	Did authors provide a description of the coding tree?	No
26	Derivation of themes	Were themes identified in advanced or derived from the data?	3.8.1
27	Software	What software, if applicable, was used to manage the data?	3.8
28	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?	Ch4/5
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Ch4/5
31	Clarity of major themes	Were major themes clearly presented in the findings?	4.5
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	4.5

3.11 Summary

This chapter has presented the study design, explaining the reasoning for choosing a qualitative methodology to answer the research question. The choice of a generic qualitative approach has been explored, against the other common qualitative approaches. This approach was underpinned by a pragmatic theoretical framework. Congruent choices of method and analysis have also been described. The conduct of the study has been explained, beginning with sampling and recruitment strategies. I have clarified my stance regarding the first phase of the study, which formed a strategy that I termed “consecutive criterion sampling”, whilst the second phase represented a convenience sample. Pitfalls in the recruitment process as well as the required adaptations were discussed. The use of thematic analysis in the interpretation of findings has been presented, as well as researcher subjectivity in the conduct of this study. Finally, methods for establishing rigour were discussed, which included introduction of the COREQ checklist, aiming for transparency. The following chapter will present the findings from the women recruited to this study.

CHAPTER 4 - RESULTS

4.1 Introduction

This chapter presents the findings and analysis of the interviews undertaken with women regarding their experience of choosing a type of breast reconstruction. The chapter begins with an overview of the demographic characteristics of the participants, and account of the purposive sampling approach adopted. This is followed by a section focusing on women's experience of breast cancer, as well as a section that describes what motivated women to choose to have breast reconstruction. These sections will aid the reader in understanding the landscape from which women choose a type of reconstruction. The themes that were developed from the interview data will then be presented, demonstrating factors that influenced women's decision-making, towards a type of breast reconstruction. The developed themes, with excerpts that represent participant accounts, are then explored and contextualised within the literature. As discussed in Chapter 3, a generic qualitative approach adopting a pragmatic interpretive framework was used for analysis. Findings from the interviews with the clinicians recruited from the two sites are reported in the next chapter.

4.2 Introduction and Overview of Participant and Site Characteristics

This section provides an overview of the characteristics of the women recruited, as discussed during interviews and extracted from transcripts. These characteristics are summarised in Table 4.1 below.

Table 4.1 – Patient Participant Characteristics

Participant	Site	Timing	Reconstruction	Laterality	Background	Interview
0101	1	One breast immediate, other breast delayed	Immediate: LD + Implant Delayed: LD + Implant	Bilateral	British	Face to Face
0102	1	Immediate	IBR	Unilateral	British	Telephone
0103	1	Delayed	DIEP	Unilateral	British	Telephone
0104	1	Delayed	DIEP	Unilateral	British	Telephone
0105	1	Immediate	LD	Unilateral	British	Face to Face
0106	1	Delayed	initially failed TRAM, followed by salvage LD	Unilateral	South Asian	Telephone
0107	1	Declined IR	*Intent for IBR*	Unilateral	British	Telephone
0108	1	Delayed	DIEP	Unilateral	British	Telephone
0109	1	Delated	DIEP	Unilateral	South Asian	Telephone
0110	1	Delayed	IBR	Unilateral	South Asian	Telephone
0201	2	Delayed	DIEP	Unilateral	British	Telephone
0202	2	Immediate	IBR	Bilateral	British	Telephone
0203	2	Immediate	IBR	Bilateral	British	Telephone
0204	2	Immediate	IBR	Bilateral	British	Telephone
0205	2	Immediate	IBR	Unilateral	British	Telephone
0206	2	Delayed	DIEP	Unilateral	British	Telephone
0207	2	Immediate	LD	Unilateral	British	Telephone
0208	2	Immediate	LD	Unilateral	French/African	Telephone
0209	2	Immediate	IBR	Unilateral	British	Telephone
0210	2	Immediate	IBR	Unilateral	British	Telephone

Initially, the intention was to recruit participants using a purposive sampling approach, aiming for six to eight patients from each site who had undergone one of the three major reconstructive modalities, as well as four to eight patients who declined reconstruction at both sites. As explained in Chapter 3 (see section 3.6), recruitment proved challenging. Given the richness of the data collected in early interviews and after discussion within the research team (AL/GC), it was agreed to recruit using a consecutive criterion-based sample of ten participants from each site. Interviews lasted on average 72 minutes at Site 1 and 54.5 minutes at Site 2, with an overall average of 63.25 minutes; they ranged from 40 to 90 minutes at Site 1 and 27 to 93 minutes at Site 2.

As illustrated in Table 4.1, acceptable variation of the reconstructive modalities undergone by participants was still achieved, despite changes to the recruitment approach. At Site 1, seven participants underwent autologous procedures, two had IBRs and one participant declined immediate reconstruction. Recruitment from Site 2 included four women who underwent autologous procedures and six who had IBRs. Only two women who had immediate reconstructions were recruited from Site 1, and only two women who had delayed reconstructions were recruited from Site 2. Two participants from Site 1 had complex reconstructive journeys. Participant 0101 had bilateral reconstruction; one breast was reconstructed immediately with a risk-reducing mastectomy and the other breast had a delayed reconstruction. Participant 0106 initially had a TRAM flap that failed (due to flap necrosis), and was followed by a salvage LD breast reconstruction.

After successful recruitment and interview of five participants at Site 1, the interviews went through a round of analysis, and a preliminary coding framework was developed. Average interview length was slightly shorter at Site 2, which I suggest could be explained by a growth in confidence and improvement of my interview technique with experience. All interviews were undertaken by a single interviewer (DL). As described in Chapter 3 (see section 3.8/3.8.1), interview transcripts were read, and re-read, to identify codes that represented factors that appeared to influence choice of type of breast reconstruction. These codes underwent rounds of analysis, to develop higher level codes, which were categorised into subthemes, and finally, themes that best represented the factors that influenced women's choice of type of breast reconstruction.

4.3 Site Characteristics

The characteristics of the different sites had the potential to influence decision-making. One of these characteristics was the surrounding population. For example, deprived communities are often associated with conditions such as obesity, or engagement with unhealthy behaviours, such as smoking (Dare et al, 2015). These conditions can affect the provision of choice, as autologous procedures are more frequently offered to those without significant co-morbidities and non-smokers (see sections 1.3.1.2 and 5.3.3). Site 1 serves an urban population with significant levels of deprivation and concomitant ill-health and social care needs. Life expectancy is less than 3 years lower than the national average. Whereas Site 2 is located in a smaller city, and the NHS Trust where breast reconstruction is provided serves a smaller population. The population's life expectancy is less than 2 years lower than the national average, with high levels of mental health problems, child and adult obesity, and many living with multiple long term health conditions. These statements have not been referenced in order to protect the anonymity of the clinicians recruited to this study. It is however difficult to make a conclusion on the effect of the local population of these sites on study findings, as both sites received referrals from smaller cities and rural areas that lacked local breast reconstruction services. Some women in this study reported travelling from these smaller cities.

The specialisation of the surgeons delivering the service also represented important characteristics of each site, as this directly impacts the types of reconstruction delivered locally. As described in Chapter 1 (see section 1.4.1), there are two types of breast reconstruction surgeons, each with their own surgical repertoire. Site 1 employed two plastic surgeons at the outset of this study, however over the recruitment period, one of the plastic surgeons left the Trust. Nonetheless, autologous flap reconstructions (including free flaps) as well as IBR were offered at this site. As recruitment continued, an oncoplastic breast surgeon was employed. One of the plastic surgeons and the new OPBS participated in the clinician interviews presented in the next chapter. Site 2 employed four OPBSs, of whom two were recruited to this study.

Consequently, IBR and LDs were performed at this site. Site 2 had an agreement with a private hospital in a nearby city, where women could be referred to a plastic surgeon if suitable for free flap reconstruction.

In Section 1.4.1 the 'hub and spoke' model of reconstructive surgery centres was introduced, describing the OPC ('hub') and the OPU ('spoke') as the recommended oncoplastic service configurations from the then-current *Oncoplastic Breast Reconstruction: Guidelines for Best Practice* (Rainsbury and Willett, 2012). Both of the recruitment sites were quite unusually configured when compared to this guidance. Take for example Site 1, with (initially) two plastic surgeons, which would represent an OPU in terms of the number of surgeons delivering the service and the estimated volume of major reconstructions undertaken per year. However, this site offered DIEPs, which as a free flap reconstruction should be undertaken at an OPC. Furthermore, as a major reconstruction centre that should have the expertise to manage tertiary referrals, an OPC should be able to offer a range of pedicled and free flaps (Rainsbury and Willet, 2012), including uncommon reconstructions (ie thigh and gluteal flaps), which were not offered at Site 1. The service at Site 2 was delivered by a number of oncoplastic surgeons (n=4) that could comprise a small OPC, and could be expected to perform a volume of procedures more comparable with an OPC too. An OPC however would also be expected to have at least two surgeons performing microvascular free flap reconstructions, which was not the case at Site 2.

There are some breast reconstruction surgeons who feel that choice is not equitable; that some surgeons have reconstructive preferences that may be imposed upon their patients (Potter et al, 2013). The different skill mix available at these two breast reconstruction units facilitated exploration of any differences between the experiences of women at these two sites. This included possible expressions of preference from the different types of reconstructive surgeons, and also whether local access to more complex procedures, i.e. access to in-house free flap BR, played a role in decision-making.

The reconstructive modality offered was also in part determined by the clinical need for radiotherapy, and its effect on the approach to immediate reconstruction. There were differences in clinical practice between the selected sites. At Site 1, women who in all probability would require radiotherapy, would normally have their choice limited to delayed reconstruction. These women would therefore experience a period of time after mastectomy (and before delayed reconstruction) with a mastectomy scar, and would be offered an external prosthetic. This experience is frequently reported upon as negative (see section 1.3). In contrast, the practice at Site 2 usually followed the delayed-immediate algorithm outlined in Chapter 1 (see section 1.3.2). These differences in practice between the two sites were significant, particularly as some participants (n=2) were aware that immediate breast reconstruction could be performed irrespective of radiotherapy, and discussed this during interviews. The distribution of women with immediate and delayed reconstructions that were sampled at each site could have been reflective of this practice at both sites.

Another important difference between the two sites was the way in which decision-making support was provided. Introducing women considering breast reconstruction to a woman who has already had this experience is recommended in national guidance (Rainsbury and Willett, 2012). The experience discussed ranges from decision-making, to surgery itself, and post-operative recovery. At Site 1, a patient support group was offered twice a year, in which all women who had had breast reconstruction, and women who were contemplating breast reconstruction, were invited to discuss the experience. One of the plastic surgeons from Site 1 usually speaks at the event, and answers questions. Those considering BR were able to meet other women who could potentially have had any type of reconstruction, and were able to have unmoderated discussions with each other. This group was not run frequently enough to provide decision-making support to all women, particularly those suitable for immediate breast reconstruction. There was however a volunteer from the group, who had undergone a TRAM flap breast reconstruction, in attendance at the plastic surgeon’s clinic. This volunteer took an active role in providing support to women and was available at all outpatient clinics, particularly for women who were choosing breast reconstruction. She would speak to any woman who wanted to know more about the breast reconstruction experience, either immediately after their appointment or arranged at a later date. The pre-surgery patient education and contact methods at Site 1 could have influenced decision-making, and therefore findings. Unfiltered discussion about breast reconstruction gleaned at a meeting could have resulted in new members adopting the opinions of the group.

The second site utilised a 'trusted contacts' model, where women were offered the contact details of a patient advisor, who had previously undergone a particular reconstruction. These advisors were selected by the team on the basis of the reconstruction they had undergone, and had been prepared to act as peer advisors, due to their specific knowledge. Contact details were provided after a type of reconstruction had been chosen; the introduction was aimed to prepare for the experience of a specific reconstruction, not to influence choice. Findings suggested that not all women were offered, or did not realise they could have access to, this resource.

Both sites took referrals for reconstruction from neighbouring cities, and some of these women were included in this study. They reported that they had access to a different local support group at their referring centre, utilised prior to attendance at the study sites, which some referenced in interviews. Their accounts suggested that these groups focused on breast cancer support as opposed to reconstructive decision-making support, but women who were post-reconstruction were reported to attend and discussed their experiences of BR with other women. A summary of the differences between these two sites is presented in Table 4.2 below.

Table 4.2 – Site Characteristics

	Site 1	**Site 2**
Location	Large UK city	Smaller city than Site 1
Oncoplastic Breast Surgeons	1 (newly appointed during the course of the study)	4
Plastic Surgeons	Initially 2, reduced to 1 during the course of the study	None
Autologous Procedures	LDs and DIEPs performed in-house	LDs performed in-house. DIEPs referred to a private hospital in same city as Site 1
Radiotherapy	Generally precluded immediate reconstruction	Did not preclude immediate reconstruction

Delayed-Immediate Algorithm	No	Yes
Support Method	Support Group/Volunteer	Trusted Contact

4.4 The Breast Reconstruction Decision-Making Experience

This section introduces the three themes which were developed after analysis of the transcripts of the participating women, representing answers to the second research question: *what experiences were important to women with breast cancer undergoing mastectomy when choosing to have breast reconstruction?* The first theme, *The Experience of Breast Cancer and Mastectomy*, illustrates how the women of this study endured mastectomy and how their treatment affected them. The second theme, *Perceptions of Normal,* describes how individual constructions of 'normal' motivated women to have reconstruction. The third theme was entitled, *Relationships Influencing Decision-Making,* which highlighted the relationships that supported these women through the decision-making experience. These themes (summarised in Table 4.3 below) provide insight into these women's decision-making experience, and importantly, provide the context from which they chose to have a type of breast reconstruction. The themes that influenced women when choosing a type of reconstruction are presented in section 4.5 below.

Table 4.3 – Themes: The Breast Reconstruction Decision-Making Experience

Themes		
The Experience of Breast Cancer and Mastectomy	Perceptions of Normal	Relationships Influencing Decision-Making

4.4.1 *The Experience of Breast Cancer and Mastectomy*

Mastectomy for breast cancer was a traumatic experience for the women participating in this study, which motivated many to have breast reconstruction.

> *"When I came round from the surgery after having the mastectomy, I felt absolutely devastated and I knew that I couldn't live like that without having the reconstruction."* (0103 – Delayed DIEP)

The trauma of breast removal was the driver that made breast reconstruction necessary. Another described mastectomy as *humiliating* (0110) whilst for others, mastectomy appeared to represent a loss of sense of self:

> *"I know it sounds really silly, but having to look in the mirror every single day and seeing a mastectomy scar and, even now, looking and not seeing what was me"* (0101 – Immediate LD + Implant and Delayed LD + Implant)

This is not unique to women undergoing mastectomy and has been reported by those who have experienced a change in appearance due to cancer, for example in head and neck cancer (Callahan, 2005).

Perhaps one of the most difficult aspects of mastectomy that many struggled with was its impact on their sense of femininity.

> *"Because I'm a woman and I think you need boobs. "* (0202 – Immediate Bilateral IBR)

> *"I just felt I'd feel more of a woman, if you like, having them reconstructed. It scared me more to know that I was going to have to go through the reconstruction but I felt ultimately I would feel more feminine."* (0204 – Immediate Bilateral IBR)

> *"Well I don't feel a woman anymore. Fourteen years ago I had a hysterectomy and now I've lost my breast, I just don't feel like woman anymore."* (0107 – Declined IR)

The two participants who had required mastectomy and previously had a hysterectomy or oophorectomy (for oestrogen dependent breast cancers), described being particularly affected. It was not just the mastectomy that assaulted their sense of femininity, but other aspects of the breast cancer treatment journey that impacted the way they perceived their womanhood.

> *"And because body image for me is very important, I'm young, it always has been, it's not a new thing, you know, I'm single so again you've lost your hair and you put weight on, all the rest of it, you don't want to be adding anything else [implying declining mastectomy] into the mix"* (0102 – Immediate IBR)

> *"…And obviously form a sexuality point of view, feeling that you're still desirable after cancer. And I think that's really significant."* (0105 – Immediate LD)

The treatment for breast cancer experienced by the women in this study often included adjuvant therapies such as chemotherapy, which resulted in hair loss. The combination of mastectomy, hair loss and weight gain impacted feelings of femininity, desirability to a partner, sexuality and body image in general.

The experience of breast cancer and its treatment affected a range of relationships for some of the women in this study. Some described an impact on relationships with friends:

> *"I've lost a lot of -, well not a lot of friends but have lost friends because … you're not helpful, you have the attitude that you finished your treatment so everything's fine, people expect you to be who you were before the cancer and it's never going to happen…"* (0102 – Immediate IBR)

Some described struggling with being the person they had become through breast cancer, which was different from how they were before. This changed the way they behaved around their friends. For example:

> *"…it's been more like friends and stuff and you get that attitude when I was sort of moaning about being lopsided and 'oh does it matter', 'well yeah it does!' and don't make me feel guilty, you know, 'would you rather be dead?', 'would you?', like what a stupid thing to say…"* (0102 Immediate IBR)

Some women did not think that people who had not experienced cancer could truly understand them, and were concerned that friends and even some health care professionals would view the decision to have reconstruction as vain.

> *"It's a weird one as well because some of the attitudes that you do get within the breast cancer world as well is if you want reconstruction, it's almost seen as vanity, it's very odd."* (0102 – Immediate IBR)

Others found that breast cancer had an impact on their relationship with their partner.

> *"Erm, it affected me and my husband, our sex life, at the time and that still affects, it's still ongoing, that is now."*
>
> *"Yes, I thought it might help but that hasn't helped, having the reconstruction with me emotionally with my husband, no."* (0201 – Delayed DIEP)

The notion of reconstruction as a solution for loss of something, as a consequence of breast cancer and its treatment (in this case loss of 'sex life') has been identified in the literature as an influential factor in choosing DIEP flap BR (Gopie et al, 2011).

The breast cancer experience and its impact on family was also influential on decision-making:

> *"I don't think I was thinking of myself more than anybody else, I think I was thinking of my family! The distress I was putting onto them more so than anything else. So that was why I ended up changing my mind from having a reconstruction all together and going down the route of going flat as well because like I wondered whether I'd accept it better. [becomes upset] Sorry"* (0107 – Declined IR)

In this account, the woman wishes to minimise distress felt by family members by choosing not to have reconstruction, as it would place further emotional burden on them. Guilt associated with having cancer was portrayed as causing distress to her family. It may also represent putting the needs of family members over and above her own; perhaps even viewing reconstruction as selfish. Guilt associated with having cancer is a recurring narrative described in the literature (Abrams and Finesinger, 1953, LoConte et al, 2008). Feeling responsible for others over oneself (the person with cancer) also appears in the cancer literature (Inhestern and Bergelt, 2018). Whatever the underlying reason for cancer having this effect, it was strong enough to influence her decision to decline immediate reconstruction altogether.

Mastectomy not only affected the way women felt about themselves, and their body, but also affected the way some women felt they were perceived by others.

> *"It's terrible to come round and to feel and to look how you do. You just feel like everyone's looking at you and everyone knows, everyone is talking and it's just not nice at all…"* (0103 – Delayed DIEP)

A clear sense of distress in social situations is conveyed. This may impact adaptation and hopes for the future, as mastectomy appeared to imply diminished social standing for some women.

> *"…if I want to think about the second marriage, as well, and who can marry with me in this position… if I feel I am uncomplete [sic] lady, so who can accept me just like in this situation?"* (0110 – Delayed IBR)

For this participant, the ability to find a new partner was thought to be reduced prior to reconstruction and she felt that reconstruction subsequently restored her confidence. Descriptions of mastectomy as leaving women feeling ‘incomplete’ and ‘unbalanced’ were common in this study.

The experience of mastectomy and breast cancer on the women in this study outlines the injurious effects of the experience, which range from loss of sense of self, to damaging relationships with friends and family. Mastectomy was perceived as an assault on femininity, coupled with loss of aspects of the feminine appearance, and loss of feeling desirable as a woman. Predominate in these descriptions of mastectomy is the sense of stigma associated with it, as if removal of the breast also removed some inherent notion of female personhood.

4.4.2 *Perceptions of Normal*

The second theme, women’s *Perceptions of Normal,* represented a commonly described motivation for breast reconstruction. Similar to the breast reconstruction literature, participants frequently chose breast reconstruction in order to look and feel normal (Boehmer et al, 2007, Gopie et al, 2011, Rubin et al, 2013, Cheng et al, 2018), evidently a response to the experience of breast cancer and mastectomy described in the previous section. However, although the word recurred in women’s accounts, the specific meaning of *normal* was different for each individual. In Denford et al’s (2011) study, four interpretations of normality were identified in women who have had breast reconstruction: *Appearance, Normal Behaviour*, *Reconstructing Normal* and *Health.* Although all the components of this framework for understanding *normal* were expressed by the women in this study, there were few references to *Normal Behaviour* (resumption of normal activities, behaviours and routines performed before breast cancer) and *Health* (normality indicated by an end to the period of ill-health). Primarily, the accounts of the women in this study referred to normal as *Appearance* and *Reconstructing Normal*, which are discussed below.

4.4.2.1 *Appearance*

Denford et al's framework (2011) first introduced *Appearance,* which was constructed of three elements: *looking like I did, looking normal to others* and *looking natural*. Similarly, in this study women spoke to the significance of appearance in relation to decision-making, as "looking normal to others" and "looking like I used to", and distinguished between these notions.

> *"There were times I didn't wear a bra at home and there was my son's friends used to come in and I was hiding myself here and there, just putting you know, big scarves round my breast, on my head, in terms of keep myself covered. And now that anybody walks in you know, I'm, you know I don't really care because I know I'm back to, as normal."* (0106 – failed TRAM followed by salvage LD)

Prior to reconstruction, appearing as normal to others required camouflage for this participant. She describes how her single-breasted appearance did not meet what she perceived as socially accepted standards of a normal appearance. For other participants, to appear normal was to get back to doing normal things, like going to the shops, or have people come over to the house, without being seen as unwell.

"*Looking like I used to*" was another element of appearing normal in this study, similar to Denford et al (2011). This was linked to an inclination to re-create the same breast size.

> *"… [The surgeon] was asking me what size. I said, 'Definitely not bigger. Either the same or smaller', and that's what I got…"* (0104 – Delayed DIEP)

Matching or even a slight reduction of the size of the pre-treatment breast seemed to be the primary aim of many participants, reinforcing this notion that what constituted normal was as previously.

> *"I didn't want to be massive or anything and I was OK with going down maybe half a cup or a cup size but if I hadn't had the implants then it would have been, you know, hardly anything, it would have been so small that why bother going through the surgery kind of thing … I was really looking forward to being able to put on a normal bra again and go I've got a cleavage! … Yeah and I'm not saying like a big massive barmaid kind of cleavage, I'm just saying a natural cleavage…"* (0101 – Immediate LD + Implant and Delayed LD + Implant)

For this participant, wearing her normal bra that provided a natural cleavage was important. Dismissal of an increase of breast size, and reference to "a barmaid kind of cleavage", distanced the normal from any association with enhancement, cosmetic surgery or any surgery that would create a sexualised body form, that might be construed as not “looking like I used to”. “Looking natural” also emerged as a type of normal in this study that was influential in decision-making, but is different from other aspects of *Appearance,* and will be explored later in this section.

4.4.2.2 ***Reconstructing Normal***

Perhaps one of the most influential aspects of returning to normal was that of *Reconstructing Normal*. This was described as an attempt to reconstruct the sense of self and identity, to regain equilibrium, something lost with mastectomy (Denford et al 2011).

> *" … it’s almost really not even about vanity, it’s just feeling -, I don't know want to say normal because I didn't feel abnormal before, it’s just feeling balanced… I just wanted it done, I just wanted to feel like my old self again in that respect.”* (0108 – Delayed DIEP)

Breast reconstruction was often seen as the path towards reconstructing not just the breast, but restoring the self to what it was before cancer. There is a clear indication in the language used by the women that reconstruction was not about vanity, but about reconstructing their self-concept. For some women, reconstruction served as the mechanism whereby they could achieve a complete sense of self.

> *“I just knew that the thing that kind of got me through my mastectomy was knowing that I was going to be reconstructed afterwards and I was going to have, you know, not ‘normal’ because you’ll never be normal again but to be whole again if that kind of makes.”* (0101 – Immediate LD + Implant and Delayed LD + Implant)

Reconstruction was described as providing a sense of wholeness, but many women were realistic in that they recognised that turning back time and obliterating the breast cancer experience was not achievable. For some, that involved recognition of the complete loss of a previous self.

> *“…people expect you to be who you were before the cancer and it’s never going to happen, so you have to try and then go into a period of mourning almost for that person…”* (0102 – Immediate IBR)

That deep sense of loss suggests that for some, what is lost through breast cancer was not completely regained with breast reconstruction.

Reconstructing Normal also referred to recreating a personal sense of femininity, by rebuilding the aesthetics of the female form.

> *"They said you can have your reconstruction larger, the same or you know, or even smaller and I told them that I wanted smaller and not so large… But not too small. To me they're part of beauty as well so not something that you can't see, or I don't want anything too small which will you know, look like it's a man's chest."* (0106 – failed TRAM, salvage LD)

The breast, and its association with a woman's beauty, is often seen as a central part of femininity and a vital part of identity, thus breast cancer and mastectomy can fundamentally challenge some women's sense of femininity (Crompvoets 2006, Denford et al, 2011). Ensuring that a breast reconstruction provided a large enough breast, to not be associated with "a man's chest" highlights how reconstruction may restore the femininity diminished through amputation of the breast. Crompvoets (2006) has suggested that reconstruction may help women to '*do'* femininity, by engaging in the labour of femininity, such as putting on a bra as previously. However, she argued that full acceptance of femininity only comes after women have addressed their deeper sense of self, or who they are after the biographical disruption of breast cancer and its treatment is complete – regardless of whether this ultimately leads to a decision to accept or decline breast reconstruction.

4.4.2.3 Summary of *Perceptions of Normal*

A desire for normality was a key motivator for reconstructive breast surgery, with many individual interpretations. Denford et al's framework for understanding normality in breast reconstruction was applied in understanding the breast cancer experience of the women who took part in this study. The women in this study sought to achieve normality by appearing normal to others, returning the form of their previous breast through reconstruction, rebuilding their sense of self and ending the period of illness. Constructions of normal also included return to exercise, caring responsibilities, and work. These individual constructions of normal, as regaining some of the way of life before breast cancer were consistent amongst these women and was part of why they chose reconstruction. This was experienced or expressed by women as an influencing factor in choosing to have reconstruction (or intending to have reconstruction – 0107). All these women appeared to subscribe to a type of normality as an influence, whether that involved meeting the expectation of having two breasts, or personal constructions of what normality entails for them.

4.4.3 *Relationships Influencing Decision-Making*

The third theme representing women's decision-making experience was entitled *Relationships Influencing Decision-Making.* The women in this study were either offered, or accessed, various sources of information/support to assist in their decision-making. Many of the relationships to which these women turned for support played a role in the decision-making process. It is clear from this study that few women made decisions without recourse to others, whether that be friends, family, partners, or support networks. This theme describes social influences on decision-making. The first subtheme, *Informational Relationships*, explores both clinical and experiential sources of information that influenced breast reconstruction decision-making. These included breast care nurses and support groups. The second subtheme, *Personal Relationships,* locates the breast reconstruction decision for women in the real world, with the people with whom women live their lives. These included the influence of the woman's partner and wider social network/community on decision-making. Another important relationship discussed by the women in this study, and often in great detail, was the relationship they had with their surgeon. This is discussed later in this chapter (see section 4.5), as surgeons appeared to play a role in influencing choice of type of reconstruction.

4.4.3.1 *Informational Relationships*

Women had access to a range of people who were sources of information, experience and advice. These people also formed part of the architecture of support for women in their breast cancer and reconstruction experience. Some of these were formally integrated, for example breast care nurses, and 'trusted contacts'. Others were accessed outside of the support offered by healthcare services, such as online forums (accessed via Facebook, for example). Personal sources of support are discussed later in this section.

4.4.3.1.1 *Breast Care Nurses*

Although BCNs were not thought to help women choose a type of breast reconstruction, they were evidently a great source of support during decision-making. Breast care nurses played a key role for many of the women interviewed, who valued them for their knowledge, honesty and dedication:

> *"My breast care nurses. All of them. I think they all deserve a medal. My breast care nurses were always there, yeah. And if I'd have wanted to know anything, I think that they would have told me the truth, yeah."* (0201 – Delayed DIEP)

> *"So whatever time of day that I phoned you know, within a couple of hours somebody always phoned me back. It was always the same day, it was never the next day. So they were really good and should I have needed more help I knew that they were there."* (0206 – Delayed DIEP)

The breast care nurses were perceived as more approachable than consultants, and women believed they had more time for them.

> *"…the breast care nurses are there more supportive, you know, …if you talk to the breast care they're there for you, you can tell them anything, you can cry with them, they put you at ease or they will go through anything that you're not sure of. Because I suppose with the consultants, I know it's not their fault but they have such a lot of patients to see that they couldn't sit with you for an hour, you know, to comfort you."* (0207 – Immediate LD)

This account shows that breast care nurses were seen as a source of emotional support that consultants were not perceived to be able to provide. Women also felt more comfortable asking questions of breast care nurses. This was important as some felt they retained little of what was discussed during the consultation, which could be an overwhelming experience.

> *"… you're there with the doctors and it is a bit sort of like bunny in the headlights… you need time to digest it all then you digest it all then you forget it all! And so if you had one of the nurses there and they were always there in the consultation room with you, if you could speak with one of them again later on then that was very helpful…"* (0209 – Immediate IBR)

The phrase 'bunny in the headlights' may also suggest a perceived differential in power during the consultation. Breast care nurses were subsequently relied upon to "*put it in a more laymen's terms*" (0209), and re-deliver the core details of the consultation. The degree of comfort and familiarity between women and breast care nurses suggests a different sort of professional relationship, possibly without a perceived power differential. This may have created an environment in which women could express emotion, but also helped them to comprehend, and therefore better retain information.

Despite the pivotal role of the breast care nurses in helping women understand what was discussed in the consultation, it was still evident that for most women, the breast reconstruction decision was made with their surgeon.

> *"… the doctors are… consulting with you about what's the best option as regards your treatment… And then the nurses would go back over it with you… obviously you weren't going to make a decision with the nurses, you'd make it with your doctor, but then it would be helpful to go over it again."* (0209 – Immediate IBR)

However, they would often go over aspects of the decision with their nurses, and in so doing, make the decision easier for women.

> *"And so I think I was able to use them as a sounding board and then they would make sense really of what I was either frightened of or concerned about or what have you. So they made that decision a little bit easier."* (0210 – Immediate IBR)

Women saw the role of the BCNs as one of elaboration, to answer questions, and perhaps even helped women clarify their own concerns.

Breast care nurses were lauded by the women in this study for their support and dedication throughout the reconstructive journey. This support ranged from emotional to informational. Women seemed to feel more comfortable with their nurses, rather than their surgeons, which often led to follow-up consultations with their BCN. During these consultations, they would revisit the details from the surgeon's consultation, answer questions and also clarify aspects of decision-making.

4.4.3.1.2 *Support Groups and Contacts*

Another component of the support network available to the women at Site 1 was the in-house breast reconstruction support group. The interview schedule was amended (see section 3.7.3) to explore the role of support groups in the decision-making process, particularly as the second site did not have a similar reconstruction support group. The aim was to assess whether support groups motivated women to choose to have reconstruction, choose a type of reconstruction, or provided more general support throughout the experience (without influencing choice). The characteristics of each site's support configuration has been described above (see section 4.3). There were mixed views regarding the value of support groups and 'trusted' contacts. Some women also accessed online support groups, which were important for their decision-making.

Most relevant to this thesis, women's narratives were read, looking for any ways in which support groups or patient volunteers might have influenced women's choice of type of breast reconstruction. There was a potential for the reconstruction clinic volunteer at Site 1 to influence choice, which will be discussed later in this section. Only one account touched upon this possibility in groups:

> *"… they were all happy with the decision they made… and that's what it needs to be... There's some ladies there that prefer the implant and the one lady is due to have hers done again this year or next year. She isn't bothered about it… that's a choice she made and she knew she'd have this done. ... So it's just everybody is an individual and it's just whatever is best for them."* (0103 – Delayed DIEP)

This participant presents a picture of the support group as an open place where all reconstructive decisions were accepted, with no impression of influence.

Those who felt that the experiences of other women were important to understand, valued speaking to other women quite highly.

> *"…you've got all your leaflets and got all the information but one word of advice for anybody that's going through it… there's nothing like speaking to somebody who's actually been through it."* (0202 – Immediate Bilateral IBR)
>
> *"I know you can talk to your family and they can be supportive but I think if you haven't been through it, it's difficult to understand how you're actually feeling…"* (0207 – Immediate LD)
>
> *"…surgeons sometimes becom[e] desensitised I think to the fact that you are a patient with cancer, [those in the support group] have had cancer or do have cancer and they have faced the same choices that you do and they've probably asked the same questions that you've asked or are frightened to ask."* (0210 – Immediate IBR)

For these women, interaction with someone who had been in the same situation was valued more highly than with family members or clinicians, as it was felt that only these women could understand them. This would not always necessitate a formal support group or ‘trusted contact’, as some reported valuing, but not requiring these, if they had existing relationships with women who had had reconstruction, ie friends or neighbours (0202, 0204). This was the only mention of a ‘desensitised’ surgeon.

Given its frequency (twice yearly), only one informant had described specifically attending the reconstruction support group at Site 1 (discussed later in this section). One woman from Site 1 had a very positive experience of her local breast cancer group, which women who had reconstruction also attended and often compared.

> *“And there’s just support there for you. You can go and you talk to them… any time you’re feeling down… you feel as if you fit in there because you’re going through what they’ve already been through… Yes, some have had reconstruction, some haven’t had reconstruction… they don’t want it, they said they’ve been through enough… They showed me theirs, some have had the implant and some had had it took off the stomach.”* (0103 – Delayed DIEP)

This support group appeared to provide the same function as the reconstruction specific support group, giving women the opportunity to engage with other women who have had different types of reconstruction, as well as peer support. There was a particular importance in seeing other women’s reconstruction. When asked if this type of group would have been helpful in decision-making for women from both sites who were unable to attend such a group, three agreed it could be valuable, but mostly in a non-committal fashion.

One woman, who was unable to attend the Site 1 reconstruction support group, found the post-clinic consultation with the volunteer at Site 1 invaluable.

> *“…having somebody stand in front of you that I could poke and prod if I wanted to, which I did – [support group volunteer] was a very nice lady – and physically see, that makes all the difference.”*
>
> *“… that afternoon, before I made the decision, I went and spoke to [support group volunteer] and she showed me her reconstruction that she had ten years ago, and it looked like a normal breast, it was marvellous. And I thought well if that is the standard of work, hell I want a piece of that…”*

> *"I think the whole package was right. I just came out from the meeting, it was a very long afternoon but I went home for the first time and slept in two months."* (0105 – Immediate LD)

Visualising the reconstructed breast, and experiencing its tactile quality during this encounter, appeared to significantly influence this woman's view of an autologous reconstruction, as she decided upon LD reconstruction that same day. Her narrative is particularly important as there was no mention of a meeting with a patient who had any other type of reconstruction. This may have contributed to more women choosing autologous options at this site. However, other women from Site 1 did not mention this volunteer at all, and this specific participant had a strong preference for autologous reconstruction, so the effect of the volunteer was considered plausible. The volunteer is discussed further in section 5.3.2.

There were also those who had less positive views of support groups and 'trusted contacts'. Participant 0108 was the only informant who attended the breast reconstruction support group at Site 1, and spoke of its practical value in seeing other reconstructions. However, she and others felt that the support aspect of the group was not really necessary for them.

> *"…[the support group] was worthwhile… from a purely pragmatic and practical point of view for me to speak to them and to see what they've had done… I think I'm just fine on my own… I don't want that to come over sounding… disrespectful of people who do, maybe it's just part of my character, I'm not that way inclined..."* (0108 – Delayed DIEP)

> *"... I'm quite a private person… I don't really like to talk about things like that. I found it quite a personal thing … to sort of like sit with people that I didn't know… I fully accept that for some people that would be good, but for me I just didn't think it was what I needed."* (0206 – Delayed DIEP)

These women recognised the need for individualised care and support pathways. They also however recognised that it was not within their character, or personality, to require such support. For these women, there was a sense of responsibility for personal healthcare, that not everyone requires institutional support.

Participants often did not address support groups as a pre-reconstruction decision support tool. Rather, they seemed to address it with focus on breast cancer support. A recurring narrative amongst women who discussed support groups was their impact on constructions of what is normal, or returning to normal. Some participants felt that attending a support group did not seem to be in keeping with their return to a normal life, as presumably they did not feel (or did not want to feel) like a woman who had breast cancer.

> *"… it's just I'm not the sort of person to go and sit in a group really… I think it's trying to sort of move on with my life ..."* (0203 – Immediate Bilateral IBR)
>
> *"…women that have had reconstructions don't go to cancer groups, we go swimming with the ordinary public now… I only went to… the special cancer group, the ladies swimming group because I was that conscious of not having a breast and wearing a prosthesis that I didn't want to go and swim in public..."* (0201 – Delayed DIEP)

Prior to reconstruction, this participant felt safe in exposing her difference in a public space with others who were similarly different. Following reconstruction, she no longer appeared to feel stigmatised, and felt able to 'pass' as normal (Goffman, 1963). Another participant felt that the experiences of women in a breast cancer support group were much worse than her own:

> *"… I didn't feel like I'd had cancer bad enough to be privileged to be there [referencing breast cancer group]. … if someone was there who had gone through what I had and we could talk and draw on our experiences then maybe but I didn't because… they were all much poorlier than I was and I felt really guilty for being there."* (0209 – Immediate IBR)

This participant had attended a breast cancer support group after her reconstruction. As she was nearing the end of her journey, or perhaps preparing for recovery/return to normal, the peer support she required was not suited to her. This suggests that different types of support at different stages of the journey may benefit some women, which may pose difficulty from a service provision standpoint, particularly as the women from this study have expressed mixed views towards groups.

Some participants accessed online support groups. They often extensively browsed the internet and gathered relevant information that informed their experience. For one, this directly impacted decision-making and her outcome.

> *"…because I had access to that Facebook group and to other women, I could say 'has anyone had this done and what's happened afterwards' and, you know, I knew quite a few women who'd had expander implant reconstruction and radiotherapy"* (0102 – Immediate IBR)

She described how she had adopted an active role in her surgical consultation, and requested immediate implant-based reconstruction despite knowledge that she would need radiotherapy (at Site 1 reconstruction would usually be delayed if radiotherapy is required). She knew this was accepted practice at some hospitals from personal accounts of those in the online group. The information she derived from this group provided her with the evidence to advocate for the reconstruction she wanted.

Overall, women's views towards support groups were mixed. There were two main viewpoints - those who felt that understanding another patient's experience was helpful and those that felt it was a more personal journey. It is difficult to make a conclusion regarding perceptions of a reconstruction specific group as a decision support tool, given how few in this sample attended, although there is the suggestion of some practical benefit. Ongoing participation in support groups did not match some women's expectations for recovery from breast cancer and subsequent return to normal life. The two most salient findings from this subsection include two instances where information received from these sources appeared to influence decision-making, in different ways. Firstly, encountering the volunteer who had had a TRAM in the past and being able to see the result may have swayed a participant to choose autologous reconstruction. Secondly, information received from the online support group empowered one woman to advocate against a site-specific trend (against irradiation of immediate implant-based reconstruction). This suggests that other women's experiences from such online groups, learning of accepted practice outside their hospital, can give greater confidence in expressing their care preferences.

4.4.3.2 *Personal Relationships*

Locating the breast reconstruction decision in the world in which these women lived was a necessary aspect of understanding the context of reconstruction decision-making. Women often made decisions after consulting their partner, and some were concerned how breast reconstruction would be perceived by their local community. These two areas are discussed below, as *The Partner* and *The Community.*

4.4.3.2.1 *The Partner*

Many of the women in this study discussed their decisions with their partners. The interview schedule included an open question about avenues of support throughout the decision-making process. However, there were no specific questions about informant identity, orientation, partner's gender or relationship status. Any mention of a partner was therefore because they were seen as an important source of support by the participant (n=11).

For some women, it was important to feel that their partner would support whatever it was they decided.

> *"I think it's partly being with him [her husband] that … made me able to cope with it because his love and support has made me always feel valued, whatever my physical state… So if I decided I didn't want the breast reconstruction he was quite happy for me to make that decision and he was quite happy to support me whatever surgery I decided to have. "* (0108 – Delayed DIEP)

For others, a more collaborative approach was taken with their partner.

> *"At the end I made up my own mind and I asked my husband for a bit of advice as well and he said "This is probably the best one" and me and him both chose to go for my belly flap and then finally for my back flap."* (0106 – failed TRAM followed by salvage LD)

Generally, reconstructive choices were made based on personal preference, with support or advice from a partner.

Some women (n=3) however discussed considerations of potential future partners as part of their decision process. In a previous extract (see section 4.4), a woman felt she would not be accepted for marriage without reconstruction.

> *"Well that [implying choice to have BR] to me did mean an awful lot because I didn't want to be single at forty eight again but I also don't want to be written off."* (0105 – Immediate LD)

Reconstruction may contribute to being seen as an acceptable potential partner in the future, for some women. There are suggestions from these accounts that mastectomy leads to loss of social standing, which can be linked to difficulties in finding a new partner.

In this study, the role of the partner in breast reconstruction decision-making was frequently discussed, and appeared to be primarily supportive. Central to the research question posed by this thesis, there was no evidence that partners influenced choice of reconstructive modality. The potential of a future partner may have encouraged choice to have breast reconstruction, for some women without a current partner. This may be linked to a perception of loss of social standing due to mastectomy. The literature suggests varying roles of (male) partner involvement in breast reconstruction decision-making, ranging from opposition to breast reconstruction to an active role in supporting it (Sandham and Harcourt, 2007); no participants voiced significant concerns of opposition in this study.

4.4.3.2.2 *The Community*

Three women of South Asian background participated in this study and there were some similarities in the accounts of their experiences in their respective communities. Firstly, these women all described an imperative to be cautious about disclosing too much, or indeed any information about breast cancer, and what treatment they had undergone.

> *"'Cause was really hard 'cause I can't talk to anybody… Only my husband and my boys – two boys … my brother and sister… they know that I had breast cancer, but they didn't know… what I've been through… I told them that got cured by the chemo, and that I had a small operation, so they didn't know … I lost my breast. So…I keep secret from everybody.* (0109 – Delayed DIEP)

Breast cancer, mastectomy and reconstruction were seen as something to remain hidden, known only to the immediate family, and even then information was carefully edited or controlled. Reconstruction was discussed in a way that suggested embarrassment, shame or potential judgement from others.

> *"I mean my house is on the main road, and everybody… a lot of men do taxi driving over here, all the Pakistani taxi drivers going to be staring at me – oh, is this the young lady whose breast was taken away, it was cut off? She's the one that suffered mastectomy? I don't want any men staring at me, I don't want anybody talking about me."* (0106 – failed TRAM followed by salvage LD)

Indeed, it was thought that public knowledge would increase unwanted attention and gaze of the men in her community, in a manner that could suggest the breast was sexualised.

There was a sense of resentment conveyed by these women, based on their perception of what their community demanded of them. First, they were victims of cancer and therefore 'suffered' or were suffering, and second, should not undergo reconstruction as it brought more suffering. Third, they should hide suffering so as not to attract attention, and therefore it was important not to present themselves as different.

> *"…you know in Asian people. They often sit next to each other and say "Oh have you suffered a lot? Oh my darling, how you've suffered a lot already. I hope you don't suffer any more. Don't go for operations any more, I think just leave it. Leave it where it is"."* (0106 – failed TRAM followed by salvage LD)
>
> *"…[why] I didn't tell my family – 'Oh, they're going to say, "Oh…it's OK. Don't do it… nobody can tell. You know, nobody can … find a difference. Why you want to go … for procedures – for the operation?"* (0109 – Delayed DIEP)
>
> *"If you are sick, everybody can say this: 'Oh, my god. Oh, you are sick.' But nobody can understand… they can take pity on you only, but they can't help you if they want to."* (0110 – Delayed IBR)

In these accounts, community members were portrayed as controlling, offering sympathy but discouraging reconstruction. There was a sense that the situation would be misunderstood due to ignorance.

> *"You know that's like being backwards [referencing her community's discouragement of having further operations]. You suffer from one thing, it's something you can achieve again [implying reconstruction of the breast] and you're not going for it. For me it sounds as if people are illiterate and the majority of Indian and Pakistanis are illiterate as well. My community certainly is."* (0106 – failed TRAM followed by salvage LD)
>
> *"'Cause, you know, the Asian people, still, they are backwards, yeah?"* (0109 – Delayed DIEP)

Another felt that breast cancer might be considered 'God's will', to be endured as a test. This woman however reinterpreted 'God's will' as providing both hope (cure) and reconstruction (as a further test) – both of which were part of God's expectation of her.

> *"…shouldn't be talking to each other what God has done [breast cancer], He's done it and that's it, what He made you suffer from it or that's it. Come to think of it if God has done this God can also cure you from it, God can also you know, he also given*

> *human beings the mentality to… carry out reconstructions."* (0106 – failed TRAM followed by salvage LD)

Nevertheless, all three women expressed isolation as a consequence of breast cancer, and had negative views of their community, with two participants describing their communities as "backwards" (0106, 0109).

Despite complying to the perceived requirement of non-disclosure, they appeared to set themselves apart, and described themselves as 'brave' or 'courageous' for not conforming to these norms.

> *"…only a couple of others came up for the reconstruction I thought I'm going to be one of those brave ones, I'm going to go for it. Yeah, I'm not going to let myself become so ugly for the rest of my life either, plus I'm going to go for it. I'm not going to be a coward."* (0106 – failed TRAM followed by salvage LD)
>
> *"I just put brave face, you know, in the relative[s] and my workplace, just to – like normal… 'Cause nobody knows that I'm feeling brave. Maybe it's me, 'cause I don't want to tell anybody [about her reconstruction], basically."* (0109 – Delayed DIEP)
>
> *"We don't need… these kind of thing [implying discouragement of reconstructive surgery]. My doctors … my nurses and the social worker…, they give me the courage… And now… I've got some courage as well …"* (0110 – Delayed IBR)

The process of reconstruction was likened to an achievement that warranted courage, and set them apart from her community. Although these participants seemed to feel they might be stigmatised, which caused them to adopt social isolation, they seemed to feel progressive and courageous when compared with others. Contrary to what they saw as the views of their community, the labour of persevering through suffering was associated with achievement.

> *"…[the local South Asian community] don't think ahead. They don't think for the next twenty years. They think if you suffer from something "I hope you don't suffer any more" but if you don't suffer of course you will not get anything. People who work hard, only they achieve something in life."* (0106 – failed TRAM followed by salvage LD)

This statement carries religious and moral undertones, which shall be discussed further in Chapter 6 (see section 6.3).

The three South Asian women recruited to this study shared narratives of isolation from their family and community, perhaps due to stigma associated with mastectomy. An aspect of this isolation was that few people in their extended family knew they had breast cancer; extended family tend to be important areas of support in South Asian culture (Gurm et al 2008, Bedi and Devins 2016). Disclosing information about breast reconstruction was limited to even fewer people, usually their husband and/or immediate family only. For one participant (0109), there was still a degree of acceptance of breast cancer and its treatment within the immediate family, and for the few extended family members told, the experience was minimised and described as a small procedure and chemotherapy; after which she knew that everybody 'felt sorry for her'.

Although the narrative of cancer generally has been rewritten in recent times (Holland 2002), the hopefulness, curability, and recovery message may not yet be assimilated in all cultural contexts. Bedi and Devins' 2016 systematic review exploring cultural views of South Asian women with breast cancer identified various ways in which these women believed that cancer was out of their hands. These included religious beliefs of karma (present and future life outcomes are based on actions from past and present lives), kismet (that divine powers primarily determine the outcome of disease) and God's will. Their review also identified a minor theme of passive fatalism, in which a small number of women believed their future with breast cancer was pre-determined, and withdrew from treatment. Bottorff et al (1999) also identified beliefs of helplessness towards cancer, in which South Asian women would not engage with prevention and detection of breast cancer. Some believed that the treatment was worse than the disease itself. These fatalistic beliefs give some insight into why members of the community of the South Asian women I studied might have discouraged breast reconstruction.

Breasts are furthermore a topic about which South Asian women often feel shy or embarrassed speaking about, as social taboo and notions of modesty dissuade discussion (Bedi and Devins, 2016). Public knowledge of reconstruction was perceived as dangerous as it might be perceived as sexual rather than rehabilitative. These accounts suggest that in South Asian communities, the stigma associated with breast reconstruction may be greater than that of breast cancer. This may explain the reduced uptake of breast reconstruction in some ethnic minorities (Nelson et al 2011, Feng et al, 2019). In anticipation of their non-compliance with community norms, the women in this study adopted a self-imposed isolation. This pattern has been noted in the literature; and some have shown that UK based South Asians were the least likely ethnic group (with breast cancer) to seek or receive support from their local community (when compared to White and Afro-Caribbeans) (Patel-Kerai et al 2017).

4.4.4 Summary – The Breast Reconstruction Decision-Making Experience

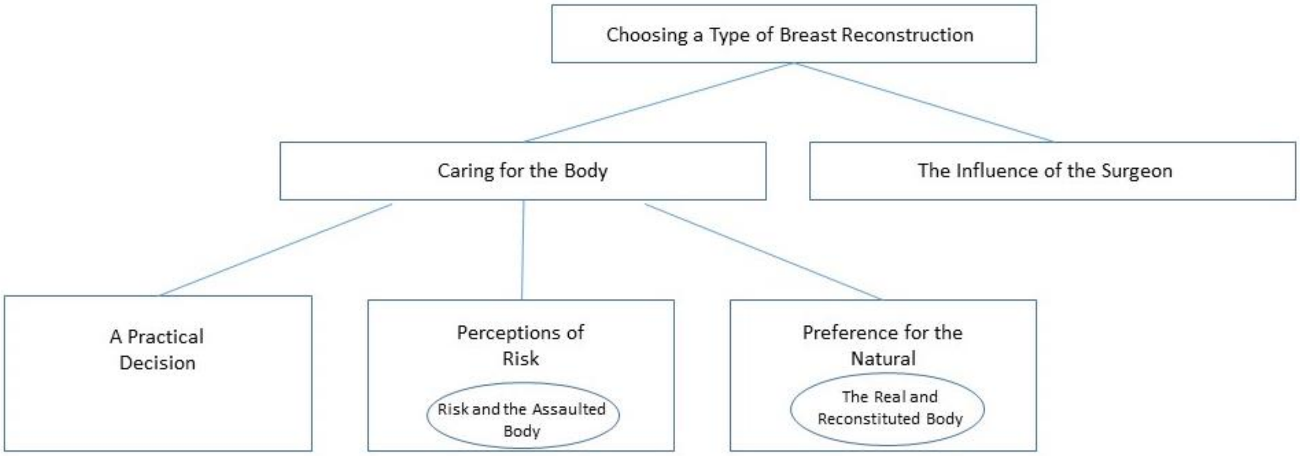
This section has introduced three themes that represented the breast reconstruction decision-making experience of the women in this study. The first theme, *The Experience of Breast Cancer and Mastectomy,* introduced the various ways in which breast cancer treatment including mastectomy affected women – it was primarily an assault on women's femininity, and contributed to loss of their sense of self. The second, *Perceptions of Normal,* described the varying interpretations of normal to which these women aspired. This desire for normality was precipitated by the injurious effects of breast cancer treatment and mastectomy. The last theme was called *Relationships Influencing Decision-Making.* This was a wide ranging theme, outlining the different sources of support that were available to women during the breast reconstruction decision-making process. Generally, these factors did not influence choice of type of reconstruction. Rather, they provide the reader with an understanding of the landscape from which women make a choice of type of reconstruction. In the next section, themes from the analysis of interview data are presented, describing how women chose a type of breast reconstruction.

4.5 Choosing a Type of Breast Reconstruction

Analysis of the interview findings resulted in the development of two major themes, which were directly related to women's choice of type of reconstruction. Consequently, these themes answer the primary research question: *what do women with breast cancer perceive as influential when choosing a type of breast reconstruction?* The first theme represents different approaches to caring for the body that influenced women's choice of type of breast reconstruction. Three different approaches were developed, entitled *A Practical Decision, Perceptions of Risk,* and *Preference for the Natural.* The second theme, *The Influence of the*

Surgeon, represents the powerful role of the relationship with the surgeon on women's choice of reconstructive modality. These are depicted below in in Table 4.4.

Table 4.4 – Themes: Choosing a Type of Breast Reconstruction



4.5.1 *Caring for the Body*

The first theme, entitled *Caring for the Body*, represents participants' views about care and treatment of the body. Each of its constituent subthemes represents a distinct approach, identified from the data, that influenced particular groups of women towards choice of a specific type of reconstruction. Women often recognised more than one of these approaches in their decision-making process. The first subtheme, named *A Practical Decision*, described a pragmatic view of treatment of the body that was grounded in the integration of the reconstructive process into women's lives and routines. Consequently, it was linked to a choice of implant-based reconstruction, primarily due to a quick recovery time. The second subtheme was entitled *Perceptions of Risk,* and represented a group of women whose decision-making was guided by their view of risk. Within this subtheme sits a small group of women represented by *Risk and the Assaulted Body* discourse; they opted for radical risk reduction due to a heightened perception of risk. They also aimed for a gentler approach to treatment, concerned with protecting the healthy body. Although the overarching subtheme of *Perceptions of Risk* was associated with choice of both autologous and implant based reconstruction, the *Risk and the Assaulted Body* discourse was linked to implant-based reconstruction in particular. The third and final subtheme was entitled *Preference for the Natural,* which explored the importance of a commonly mentioned trope amongst women: the desire for a natural reconstruction. Also within this subtheme, there sits a small group of women represented by *The Real and Reconstituted Body* discourse; their decision-making was founded upon a moral discourse that implied a pejorative view of breast implants. Both the *Preference for the Natural* and *The Real and Reconstituted Body,* focused on what women perceived as 'natural' and 'real', thereby encouraging choice of autologous reconstruction.

4.5.1.1 *A Practical Decision*

For some women (n=7), their choice of reconstruction was based either primarily, or in part, on a discourse of practicality. This describes an approach to caring for the body, in which it was required that any bodily treatment would integrate into their personal lives, whether that took into account caring responsibilities, work, or a preference to move on from the period of ill health. Reconstruction was certainly important to these women, however their preference lay more towards a return to 'normal life', and reducing disruption as best possible. These requirements were met by choice of implant-based reconstruction, as reduced invasiveness, procedural duration, recovery time and inpatient stay meant they would be able to achieve their reconstructive goal.

This approach to caring for the body was associated with a quick return to 'normal', thereby reducing disruption as best possible. When asked what influenced her choice of type of reconstruction, one participant responded:

> *"I think to look as normal as possible as quickly as possible. That's probably two things…"* (0203 – Immediate Bilateral IBR)*
>
> **repeated excerpt*

Decision-making was determined by having the least impact on other activities, roles and responsibilities associated with normal life.

> *"… exercise is important to me I didn't want to run the risk of something happening, you know, if you're taking muscle and all the rest of it that's going to affect that, didn't*

> *want any more interruption to my life than was entirely necessary I suppose. "* (0102 – Immediate IBR)

> *"… it's not local, you know, [city of Site 1] isn't a million miles away but, you know, I'm a single parent of yes grown children, they're 19 and 21, but they don't drive. I also look after my mother who's 81. I want to get back to work as soon as possible, you know, I've had long enough off work…"* (0203 – Immediate Bilateral IBR)

Caring responsibilities and work were commonly cited reasons necessitating a quick return to normal life, and therefore a practical approach to reconstruction was required.

For some, practicality entailed a quick reconstructive journey, after which the cancer experience itself could be speedily left behind.

> *"I wanted a breast there, I didn't want to be lopsided and it just seemed like the best option to get it all over and done with, not think about it and then think oh well I will need some more surgery afterwards, just to get it all over and done with really, yeah. And it would be the best option for me, yeah."* (0209 - Immediate IBR)

> *"Yeah and I suppose, you know, trying to put it behind me as much as possible, you know, trying to get back to normal as soon as possible as well."* (0203 – Immediate Bilateral IBR)

These women were not denying they had cancer, but saw a particular reconstruction as providing resolution to an interruption. One described damage that needed to be repaired speedily. Implant-based reconstruction was the clear choice for these women, as it offered a solution that could achieve reparation, 'get it all over and done with' and move on from that part of their life. This type of reconstruction also provided the best opportunity to practically care for themselves and reduce further interruptions to normal life, without need for future surgeries.

It is important to note that although many of the women who chose implant-based reconstruction also provided risk-based rationale for their choice, one participant did choose IBR for entirely practical reasons.

> *"… first of all, my son, he is not feeling well. He is a kidney patient. And, secondly… there is no one who can look after my son… when I did discuss this matter with my consultant and they said – they give me the suggestion you can talk with Social Services… straight away the Social Services, they become active and they said, 'OK.' They came in my house and they said, 'OK, we can help you and we can take care your son, and you need to go to the – for the operation.' "*

> *"… this [referencing IBR] is the smallest surgery and your son, he in the care of the Social Services, and it's very, very small time for you, and he – because I can't live without him and that's why."* (0110 – Delayed IBR)

This participant was a single mother who required social services to arrange foster care for her son whilst she was admitted for her procedure. Implant-based reconstruction was the only reconstructive modality that could support her caring responsibilities, and risk was not mentioned as a concern for her.

The women represented by *A Practical Decision* often held a pragmatic view of what breast reconstruction was meant to achieve for them in the context of returning to their normal life, and as such implant-based reconstruction met those needs. It was a frequently discussed aspect of the decision-making process that quickly excluded autologous reconstruction as an option for many women. Although the same women who chose implant-based reconstruction cited both practical reasons and risk reduction rationale, which could suggest conceptual overlap, one woman did choose IBR for solely practical reasons, and this was thought to be potentially transferable to other women choosing breast reconstruction.

4.5.1.2 *Perceptions of Risk*

Women's perception of risk was the second subtheme, describing an approach to caring for the body. It also directly influenced choice of type of reconstruction. Women usually discussed risks that concerned them the most, or ones they perceived as likely. Generally, concern for operative risk led women to make a practical choice for implant-based reconstruction. Various aspects of the surgical procedure were discussed by women as contributors to overall perception of operative risk – these included time related elements (procedure duration, recovery), complexity/invasiveness, scarring, and potential complications, such as flap failure.

> *"… it [referencing DIEP] would have been a far more intense operation… I wanted an operation that I was going to get over a lot quicker... It [referencing IBR] was a smaller operation if you like and one that you got over a lot quicker."* (0204 – Immediate Bilateral IBR)

> *"…it was where they use your own tissues to reconstruct it which… friends of friends, had had… it worked out in the end but it's been a longer road than I've been on, you know, they'd had problems and more surgeries and trying to rectify it and infections and things"* (0202 – Immediate Bilateral IBR)

Preference for a procedure that was less 'intense' or 'small', thereby speeding recovery, was a common trope expressed by these women. Part of ensuring a quick recovery included reducing the duration of the overall surgical journey. This participant's response clearly outlines the view that reconstruction should be minimally invasive:

> *"The implants because there's less scarring. To use your own tissue you're putting yourself through even more bigger operations, longer to recover and then you've got loads more scars over your body, whereas with an implant they can possibly use the same scar that you've had your mastectomy on and do it that way…"* (0107 – Declined IR – Intent for IBR)

Although many describe multiple risks, some were concerned with particular procedural risks such as preventing damage to the arm or the shoulder through an LD flap reconstruction:

> *"…[LD reconstruction] then would cause some difficulty with my arm movement for a while, that would be yet another scar in my back. Again, maybe longer recovery time because there'd be another surgical site."* (0203 – Immediate Bilateral IBR)

Other participants mentioned a range of elements to emphasise the cumulative risk of autologous procedures:

> *"I just wanted the least traumatic and invasive surgery possible because of everything that I was going through and that my body was going through, I just kind of thought I don't want that level of operation, just don't want the recovery time, I don't want the trauma to my body."* (0102 – Immediate IBR)

> *"So reducing obviously scars, getting over different cuts as well, I thought it would be an easier operation to get over … I thought that was the best way to go. It was a smaller operation if you like and one that you got over a lot quicker. So that was my reasoning for it anyway.* (0204 – Immediate Bilateral IBR)

These combinations of surgical risks appeared frequently, and very quickly discouraged any thoughts of autologous reconstruction.

> *"I was offered like the DIEP but, you know, I saw the pictures of that and I thought the scar was just a bit too much of a scar, too big an operation, you know, yet another*

> *huge operation at some point down the line, you know, so I felt as though that was the best option for me at the time really"* (0203 – Immediate Bilateral IBR)

Sometimes, the particular aspect of risk that they sought to limit was not explicitly defined, and instead, general adjectives such as 'big' or 'huge' were used to describe autologous procedures, illustrative of how the duration of the procedure and its invasiveness had become conjectured. In the previous extract, scarring may have also indicated more than simply surgical risk; for some scarring held deeper meaning.

> *"…having to look in the mirror every single day and seeing a mastectomy scar and, even now, looking and not seeing what was me…"* (0101 – Immediate LD + Implant and Delayed LD + Implant)*
>
> **repeated excerpt*

Even following reconstruction, the post-operative scars were linked to a loss of the sense of self. Scarring (or potential scarring) in BR can contribute to some women describing difficulties in rebuilding a normal sense of self (see section 4.4.2.2), not solely due to aesthetic concerns, and could influence choice.

A major element of risk that these women often focused upon was fear of flap failure.

> *"…I just got this thought that there's a possibility that the tissues, it wouldn't take and it'd be rejected and then I'd end up in more of a mess and you've only got so much skin and fat and tissue! "* (0202 – Immediate Bilateral IBR)
>
> *" Yeah, so I think obviously the more that you're mucking about with blood vessels and live tissue probably the greater chance of something going wrong."* (0102 – Immediate IBR)

These women may have even implied that autologous reconstruction was wasteful, and/or reckless. These representations of the likelihood of operative complications occurring appeared to affect these women differently than women who chose autologous reconstruction. Complications that were not very common, such as flap failure, were either communicated to these women, or interpreted by these women, as high probability complications. Perception of risk is difficult to quantify, for example, the 2-3% chance of a flap failure of the DIEP (Gilmour et al, 2021) may resonate with women differently based on individual interpretation of percentage chance. Although she didn't opt for IBR, Participant 0101 explained how her experience changed her perception and/or tolerance of risk.

> *"The other option I think why I went for the LD flaps was because of the success rate, at that point myself and my husband were told it's practically 100% success rate of the flap taking… whereas other options there was a risk, albeit small but there was a bigger risk of it not working or it failing. And I think because of what I'd been through the preceding year… I'd had a year of treatment, things like that, I wanted to have my reconstruction but I think at the point me making that decision it had to be based on what was the safest, what I knew was going to work …"* (0101 – Immediate LD + Implant and Delayed LD + Implant)

Personal circumstance may also increase or reduce perception and/or tolerance to risk, for example caring responsibilities may reduce tolerance to risk (0203).

Women who chose autologous reconstruction mostly had much less concern for risk of complications, contrary to those who chose implant based reconstruction. These women similarly utilised a range of procedural elements to reference overall risk, including time of recovery and procedural duration.

> *"So the lower abdominal, that's going to be – that will take time to recover and long hours – ten to 11 hours going to be surgery. So…I just only chose that one for – so I can feel like a real. … like same feeling that my other breast. That's why I went for the abdominal one..."* (0109 – Delayed DIEP)

Autologous flaps are often described to women as feeling 'natural', analogous to a real breast (or at least more so than an implant) (Somogyi et al, 2018). Preference for this type of reconstruction played a role in the decision to undergo a procedure with increased operative risk, and a potentially longer recovery time:

> *" I suppose how long you'd recover… or how long you'd be in hospital but it didn't bother me because I just thought well I'll stay there … as long as you need to... It didn't worry me too much, no… it wasn't an issue"* (0207 – Immediate LD)

There was still an appreciation that reconstructive surgery was major surgery, however it was felt that if a risk was going to be taken, then it should be for the procedure that suited them best.

> *"And I realised that it was the biggest operation that you could have that I was wanting, but…[laughter]…that's the one I wanted. And if [plastic surgeon] hadn't*

> *agreed to that…I don't know as I'd have gone through with it (reconstruction)."* (0104 – Delayed DIEP)

> *"…maybe that's not the best tactic to take but I just sort of thought in for a penny, in for a pound, you know, if I'm going into surgery and they're going to put me under anaesthetic, I might as well have the surgery that I feel is the best for me…"* (0108 – Delayed DIEP)

There was often certainty that the procedure that suited them, irrespective of its complexity, was the only procedure that they would accept, with some preferring no reconstruction if this were not to be available to them. They had a clear appreciation for the possibility of complications.

> *"Complications? There was a rather large long list... And I was unfortunate to have some complications... I am quite an intelligent person and understand that there's going to be certain people that do actually get the complications and I happen to be one of them."* (0105 – Immediate LD)

They typically accepted complications in stride. Some may have chosen autologous reconstruction after weighing positives and negatives. For example, surgical risks were offset by the rewards of autologous reconstruction, such as a natural feel, reward in abdominoplasty, and 'natural' response to bodily changes.

Although there was a clear delineation in the approach to operative risk for the women choosing autologous flaps versus those who chose IBR, there were some particular risks that worried the women who chose autologous reconstruction.

> *"I said straightaway I didn't want an implant. I think it's because of the risks of the implant, you know, that you read about and that's been on the news..."* (0207 – Immediate LD)

> *"…, stuff I've read in the media about them leaking or seeping into your system … I just didn't feel comfortable with having an implant."* (0108 – Delayed DIEP)

The risks associated with breast implants were generally a significant concern to women who chose autologous reconstruction. Just as the women who chose implant-based reconstruction often had an inflated perception of the frequency of autologous flap failure, women who chose autologous reconstruction perceived implant risks as frequently occurring. It appeared that both of these groups of women avoided choosing the procedure that was associated with the risk that concerned them the most.

Given these strong views that discourage choice of breast implants, it is worthwhile exploring some of their roots, in particular the contribution of the media. In 1992, the FDA (Food and Drug Administration, the medicines regulatory body of the USA), restricted implementation of silicone gel implants on the American market, due to issues with rupture and leakage of silicone, associated with the development of autoimmune disorders (Palley, 1995). Although saline-filled silicone implants were not restricted, sales of these implants also suffered as women became fearful of implants, due to a combination of the FDA ban, negative publicity by the media, and the support of legal entities in securing large claims for victims (Cohen, 1994).

A further concern regarding breast implants occurred in 2010, when Poly Implant Prosthese (PIP - a French manufacturer of breast implants) withdrew their products from the UK market, due to fraudulent usage of an unapproved type of silicone gel (National Health Service, 2019). PIP implants were found to have an increased rate of implant rupture (reported by some as high as 31.6%), an estimated 2-6 times more likely than non-PIP implants (Wazir et al, 2015, Department of Health, 2012). Although there was no evidence of toxicity, PIP breast implants were recalled (Wazir et al, 2015). All breast surgery implant providers were advised to contact patients with PIP implants for review, advising that the implant should be surgically removed if there was any sign of implant rupture (Department of Health, 2012).

Similar well-publicised health scares include the MMR (measles, mumps, rubella) vaccine and autism link, first suggested by Wakefield et al (1998), which was quickly and categorically debunked by the scientific community (Anderberg et al, 2010, Chang 2018). Correction of this misinformation took years (longer in the USA than in the UK), with reduced MMR uptake for 5 years in the UK (Chang 2018). There was also reduced uptake of other ‘non-controversial’ vaccines (‘the spillover effect’) (Anderberg et al, 2010), and there still remains a strong anti-vaccine community. More recently, there has been a well-publicised health scare with vaginal mesh in pelvic floor dysfunction (Izett-Kay et al 2021). Mesh-related complications have sparked litigation, and vaginal mesh has been temporarily suspended in the UK (Izett-Kay et al, 2021). The power of the media and its long-lasting effect on health perceptions were well noted in these instances. Given the pervasive anti-vaccine sentiment stirred by Wakefield et al’s claims, despite being completely unfounded, it is understandable that media-driven health scares when there are associated physical complications may leave lasting impressions on many women.

Despite stringent legal requirements now in place to assure the safety of breast implants, the negative image of implants endured for women who chose autologous reconstruction. Many who chose autologous reconstruction interpreted breast implants as either high risk or unacceptable risk. Interestingly, women who preferred implant-based reconstruction felt that these risks had now been addressed by improving the quality of implants.

> *".. everything [referring to implants] is virtually as safe as can be now"* (0107 – declined reconstruction – Intent for IBR)
>
> *"And I don't know whether it's naïve of me but I think … people have learned from difficulties that people have had with implants, I probably felt more secure that it was now a safer option"* (0203 – Immediate Bilateral IBR)

However, as above, the evidence suggests that there is a 2-3% chance of flap failure after a DIEP flap reconstruction (Gilmour et al, 2021), whilst there is a 9% chance of implant loss at 3 months, for women having immediate IBR (Potter et al, 2019). So although many women chose implant-based reconstruction due to concern for autologous flap failure, the procedure they chose (or would have chosen) was associated with a higher risk of reconstructive failure. Relevant to the comparison of figures provided, women discussed risk in terms of specific complications, combinations of complications, or overall risk, however they discussed the likelihood of occurrence qualitatively; no women discussed risk in any numerical form (apart from a single mention of 'practically 100%' – 0101). Women were also not explicit in how risk was communicated to them. They were clearly advised of complications by their surgeons, but it was unclear whether numerical figures were provided, or how the risks of different procedures were compared.

This section has introduced risk perception and the central role that it plays in the choice of any type of reconstruction. Women often used individual or combinations of risks (invasiveness, duration, recovery, etc.) as a proxy for overall 'riskiness' of a procedure. Interestingly, women did not disclose risk in numerical form, although they may have interpreted risk presented as a number differently. The salience of a selected risk to a woman appeared to be highly influential of their choice of a type of reconstruction (see section 6.4 for further discussion of salience). For example, those who prefer autologous reconstruction find salience with tissue based reconstruction because implant-based risks concern them greatly. Conversely, women who prefer implant-based reconstruction are more worried by risk of operative complications and recovery time. It is unclear however, whether women choose a procedure and then utilise their perception of the risks of the alternative to defend their choice, or whether their choice of procedure is based upon their view of associated risks. It is also important to recognise that risk perception is naturally a function of risk communication. Both the manner of the communication of risk, including body language and intonation (which would not be evident on a transcript), as well as the individual risks themselves, form important components of risk communication. Risk will be addressed further in Chapter 5 (see section 5.4) and in the discussion (see section 6.4).

4.5.1.2.1 *Risk and the Assaulted Body*

The narratives of the women represented by the *Risk and the Assaulted Body* (n=4), explored the self-concept of a small subgroup of women who expressed a risk-based discourse. These women utilised language that suggested a complex discourse in caring for the body. They held a system of beliefs that perhaps stemmed from an alternate view of the healthy body, in response to the assault of cancer and its treatment, advocating for gentler treatment of the healthy body, but radical risk reduction elsewhere. They aimed to preserve what were seen as healthy areas of the body through implant-based reconstruction, but were also aggressive in their approach to the treatment of the cancer.

Gentler Treatment of the Healthy Body

Firstly, this group of women did not approve of tampering with areas of the body that were perceived as healthy, which autologous reconstruction necessarily entailed.

> *"…I just didn't want… to be mucking about with muscles and all the rest of it, because my life had been interrupted so much already and, you know, I wanted to try and get back to being able to run and doing those kind of things again and so I just didn't want*

> *to go down that route of, you know, like I say, mucking about with other bits of my body if I didn't have to. "* (0102 – Immediate IBR)

This participant offered a similar excerpt earlier, but in this specific account, emphasis was placed on less assault of the integrity of the body. These sentiments resonate with the findings of Boehmer et al's 2007 study. They interviewed lesbian and bisexual women, who gave preference to body strength and physical conditioning when choosing a type of breast reconstruction, over its aesthetic result. In that study, some women chose a tissue expander based reconstruction to avoid damaging remaining healthy body parts. Autologous reconstruction was also perceived by the women in this subgroup as an unnecessary tampering with healthy areas left after cancer treatment, and therefore as impeding a return to normal life and recovery.

> *"… the final bit that made me change my mind for the implants really I think was when I saw the picture of the scar from the tummy tuck bit of the DIEP flap operation that I just that was a scar too many really. It just looked awful. So, you know, I don't look very good now but at least I haven't got yet another scar or waiting to have yet another huge scar as well."* (0203 – Immediate Bilateral IBR)

Prevention of unnecessary tampering of healthy areas appeared to include scarring of the skin. These women were particularly perturbed by the concept, and often the aesthetic of scarring, much more so than women who chose autologous reconstruction.

Choice was mainly determined on the basis of limiting risk and choosing the easier option, to avoid harming what was already a damaged body.

> *"I guess I just wanted to make things as easy as possible for myself at that point I guess because, like I say, obviously you're having everything else done, chemo and operation after operation, so I guess it was just like I don't want to make things harder "* (0102 – Immediate IBR)

This participant chose implant-based reconstruction as it offered less complexity and therefore would not complicate an already arduous cancer journey, involving adjuvant therapies and multiple procedures.

Radical Risk Reduction

For these women, their desire to limit risk to healthy body parts also influenced their view of the risk of contralateral breast cancer/recurrence of breast cancer. The majority of the women who chose IBR viewed their healthy breast as ‘risky’, and had deep concern for contralateral breast cancer. They requested contralateral prophylactic mastectomy (CPM) in the absence of a known breast cancer related syndrome, such as BRCA1/2. The surgeon involved in these cases would arrange referral to a psychologist for assessment and explore the patient’s rationale. Three of the participants from the second site opted for immediate bilateral mastectomy (including CPM) with bilateral IBR (0202, 0203, 0204). Three other participants had undergone unilateral IBR, but were actively attempting to arrange CPM and reconstruction (0102, 0205, 0210 – NB 0205 and 0210 were not included in this subgroup as although they had initial IBR, they now hoped for bilateral DIEP). Five of these six participants were recruited from Site 2. It is unclear why there was a preponderance of CPM at this site and why it seemed there may be a possible link between IBR and CPM (accepting that this sample is not statistically representative). No particular difference in the presentation of risk was made clear by these women’s accounts (compared to women of Site 1). The evidence suggests that it is usually patients who initiate dialogue regarding CPM (Ager et al 2016).

Radical risk reduction appeared to be the motivating factor for women who opted for contralateral prophylactic mastectomy.

> *“… that’s why I went for the double mastectomy … my mind-set was just get rid of all the tissue, as much as you possibly can to reduce that risk and as much as any risk can be reduced, for my own peace of mind.”* (0202 – Immediate Bilateral IBR)

Any remaining breast tissue was a source of distress, the removal of which seemed necessary for peace of mind. This is well documented in the literature (Covelli et al, 2014, Tollow et al, 2019). Radical risk reduction appeared to be a central aspect of an overarching narrative of exerting personal control of the cancer experience which also included shaving her hair off before potential hair loss through chemotherapy:

> *“I went to my hairdresser, who’s a very good friend, and she’s 14 years clear of breast cancer as well, and I said ‘will you shave my hair off’ and she said ‘of course I will’ and she did and I needed to take control of things before they took control of me.”* (0202 – Immediate Bilateral IBR)

One woman who had opted for future CPM was consistent in her pursuit of radical risk reduction with her initial procedure. She also exerted control of her cancer experience by advocating for her preferred mode of treatment despite what she described as barriers from clinicians – she was successful in this endeavour.

> *"They had said to me … 'oh we're going to be really aggressive, we're going to give you this chemotherapy and then you're going to have to have radiotherapy'… I just found it a bit weird that with young women they go 'oh we're going to be really aggressive but then we're going to give you the least aggressive operation' … 'oh we'll do a lumpectomy because obviously you're a young woman and we want to try and save your breast, blah blah blah' and it's like well that's not really a concern, I just want to be alive in ten years' time…"*
>
> *"…so I made the decision I was like 'I want a mastectomy, I'm not going down the lumpectomy route, absolutely not' … so breast surgeons were still pushing for the lumpectomy even though I said 'I'm not doing it, not having it'* (0102 – Immediate IBR)

She did not find wide local excision ('lumpectomy') with adjuvant therapies aggressive enough for her perception of her cancer risk. This is consistent with the earlier statement that any remaining breast tissue was a source of distress. Her statement suggests a heightened sense of fear of cancer, which seemed common in those opting for CPM.

In summary, the narratives of these women may represent a distinct set of values, in which they prioritised preservation of the healthy body, and radical risk reduction, as a response to the assault of cancer and its treatment. Although these women discussed different types of risk (procedural and cancer), risk reduction was a central concept to the women of the *Risk and the Assaulted Body* subgroup. For some, this necessitated choice of contralateral prophylactic mastectomy, which appeared to reduce distress for these women, as it helped manage a heightened sense of fear of cancer. The heightened concern for risk for these women necessitated choice of implant-based reconstruction.

4.5.1.3 *Preference for the Natural*

The final subtheme that explored how the women of this study cared for their bodies was entitled *Preference for the Natural.* It represents a large group of women (n=10), who described the most desirable outcome from breast reconstruction as one that was perceived as being natural. This was in keeping with findings from the qualitative evidence synthesis presented in Chapter 2. 'Looking natural' was also recognised by Denford et al (2011) as a form of normal

Appearance in their interpretative framework, as a normal breast was expected by some women to have a natural shape. A natural reconstruction was described as the primary criterion upon which many based their choice.

> *"Natural, to have it as natural as possible. That would be my number one... Do I need to go two, three and four?"* (0105 – Immediate LD)
>
> *"… the most important thing for me was that it looked natural… I don't know what else would be important, apart from it looking natural."* (0201 – Delayed DIEP)

Many participants saw implant-based reconstruction as unnatural.

> *"The natural look, more of a natural look than with an implant, that was the one that pushed me most. I was more thinking of that one rather than the tummy tuck."* (0103 – Delayed DIEP)

Looking natural appeared to be the desirable outcome of breast reconstruction, which even outweighed the benefits of the abdominoplasty. It was not viewed as achievable with IBR and usually motivated choice of autologous reconstruction, suggesting that the shape of the breast created by an implant was not perceived as normal.

> *"I would imagine that from actually having like the DIEP flap, you would have been able to achieve a more natural look, because you can kind of shape it more …"* (0201 – Delayed DIEP)

Both main types of autologous reconstruction were thought by women to be natural, as they could be more easily shaped to provide a natural look.

A narrative which emerged in relation to decision-making in breast reconstruction was related to 'age-appropriateness.'

> *"Because I hadn't got a lot of fat on me back they said off me stomach would be better. There was more there to play with and it was more natural, which is what I wanted, a more natural because with me being old and I didn't really want implants in."* (0103 – Delayed DIEP)

'Age-appropriateness' was intricately linked to being natural.

> *"I think it was a lot to do with like with me ageing like as I get older, I thought the muscle one was better because it would -, because it's my own body, it's part of my own body, it would age with me naturally … And I'd look the same or probably better, I don't know!"* (0207 – Immediate LD)

Autologous reconstructions are often presented by surgeons to women as offering longevity coupled with a natural appearance that matures proportionately with the body. In contrast, implants are designed to maintain their post-surgical placement, which would not allow for the reconstructed breast to drop lower with age (whilst the other breast does). For participants for whom this was important, an advantage of the autologous BR was that it accommodated the 'natural' process of ageing, enabling women to have a breast that continuously appeared normal for someone of their age. Throughout this study the concept of looking natural was intimately linked to choice of autologous breast reconstruction. This strong preference for a natural reconstruction typically outweighed some of the disadvantages of autologous procedures, such as increased procedural duration, recovery time, and complications.

4.5.1.3.1 *The Real and Reconstituted Body*

This subtheme was developed upon the views of a smaller, but distinct, subgroup of women within the group represented by the *Preference for the Natural* theme (n = 4); they embraced a moral discourse concerning breast implants, in their choice for autologous reconstruction. They similarly expressed a very high tolerance for perceived operative risks such as invasiveness and procedural duration, but the other women represented by the *Preference for the Natural* theme did not indicate belief in a moral discourse. This section places particular attention to the language used by women to describe their chosen course. This attention to language relates to the notion that all words represent the concepts they express (Lakoff and Johnson, 1980). Introducing this discourse began with descriptions of being, or feeling natural, distinct from simply looking natural.

> *"So I don't like foreign bodies [implying breast implants] in my body anyway. [My husband]'s aware of it, I know. I'm aware of it and it's something I'd rather not go for, you know be myself, be natural."* (0106 – failed TRAM followed by salvage LD)

Being natural went beyond creating a form that was natural, suggesting that it somehow was truer than simply looking natural. It incorporated a sense of being honest, true to oneself, and that in order to maintain a sense of self, it required choosing a reconstruction with the 'near to natural' as the aim:

> *"As much as I would like to have had my breasts done, having lost seven stone it you know, sort of gone south, it was never really a thought that I would have any implants in it. To me they look false, so the fact that it would be natural or as near to natural as possible with the LD flap [implying that this is what she wanted her breasts to look like]."* (0105 – Immediate LD)

Being natural represented the antithesis of being 'false'. An implant was not seen as acceptable especially as the body had naturally changed, described as 'gone south' due to weight loss. So choosing to be natural also related to being sympathetic to existing shape and form. The juxtaposition of being true to oneself by being natural, and aversion towards 'false' implants, suggests a moral discourse inherent in breast reconstruction decision-making (for these women), and underpins the subgroup of *The Real and Reconstituted Body*.

> *"Go for your own body's rather than having to go for foreign bodies. Don't go for things like silicone. Don't go for saline, water. Don't go for which is something not, you know, which is not real. Go for something which is real, it's good."* (0106 – initial failed TRAM then salvage LD)

'Foreign bodies', or implants (referenced to as silicone, and 'saline water'), were often discounted, sometimes quite vehemently. Fear of something conceptually foreign is evident in the literature (Martin, 1990). For these women, the concept of 'foreign' was related to not being of the body, external, and therefore not real - even potentially bad. In contrast, there was a 'realness' in autologous reconstruction, which was 'good'. These notions of good and bad, natural and foreign, real and false, suggest a moral discourse more commonly associated with breast implants in cosmetic surgery.

Such pejorative views of implants had been developed by many women in this study, primarily through connection to TV personalities or actors.

> *"…in my head I thought I was going to wake up with Pamela Anderson one side and me the other. So even though I'd been told 'no, it'll be OK, you'll look fine', that's what I'd got in my head."* (0205 – Immediate IBR)

This participant initially associated implant reconstructions with Pamela Anderson (the actress and 'sex symbol' whose cosmetic breast implants were widely reported upon) and the sexualised body, despite reassurance from her surgeon. The breast implant was thought to compare negatively to the 'real' her, on the unaffected side. Although this participant agreed to an IBR, this was a short term compromise as she intended to have an eventual DIEP as part of the delayed-immediate approach. Some participants developed a moral discourse which located implants as unhealthy, associated with certain types of women/behaviour and even possibly linked with psychological problems:

> *"…if you've got a younger person she might be very happy having an implant because it's all the rage, be it the wrong reason to have it but you could be having a young Katie Price kind of person, you know what I mean?... Because she's had that many implants hasn't she? And increasing, decreasing, I mean that's surely not, it's not good for your health and well, I think she's got psychological issues myself but there you go."* (0105 – Immediate LD)
>
> *"…it's not a page 3 sort of cosmetic thing in my view … it wasn't really in that sense a cosmetic thing… I didn't want foreign matter, even with two breasts I'm not the type of person who would have said oh yeah I'm going to go and get some cosmetic surgery to make them bigger or whatever, I'm not that type of person, I wouldn't have that done."* (0108 – Delayed DIEP)

These excerpts illuminate the use of a moral discourse to articulate the rationale underpinning decision-making and discounting breast implants. There was the suggestion that cosmetic breast enhancement was morally suspect. A number of the women involved in this study adopted this narrative to outline the reasoning behind their choice of an autologous reconstruction. Although both autologous and implant-based reconstructions were done to restore what was lost in cancer treatment, IBR still carried moral connotations due to its link to cosmetic surgery. Interestingly, the reassembling of tissue that occurs with autologous reconstruction was viewed as morally acceptable and not akin to cosmetic surgery (or enhancement). Indeed, women were clear (as discussed earlier – see section 4.4.2.1) that they did not want reconstruction to increase their breast size.

In contrast, the abdominoplasty required for the tissue transfer in abdominal flap BR was seen as positive:

> *"That (abdominoplasty) was a big plus. Yes. 'Cause I've never had – even as a child, when I was growing up, I never had a flat stomach. I always had a podge, and the thought of that was quite appealing. You know, I felt like I'd been through a lot and that this was a positive thing to – you know, a bit of pay-back, sort of thing, I suppose."* (0104 – Delayed DIEP)

Instead of a morally suspect enhancement, the abdominoplasty was viewed by some (but not all women in this group) as a reward, earned as a consequence of completing the work of breast cancer treatment. Another benefit of these procedures included facilitating a further natural process apart from ageing, namely that of weight gain and loss.

> *"…when you lose your weight [the reconstruction will] go down with you, if you put your weight on it will of course be very natural, you will also have the bigger breast as well. So it's part of me, although I took a hard step, a step which was hard, but pays well at the end."* (0106 – initial failed TRAM followed by salvage LD)

Like providing a natural result that accommodates change and ages with women, autologous procedures are often presented by surgeons as reconstructions that will change in proportion to one's weight. There is again the notion that autologous reconstruction is associated with a payoff, that investment in an arduous process reaps rewards. There was a clear expression of deeper value in these procedures.

> *"the reason I chose the one I wanted because everything that is me, it's from me and it's part of me and it's sort of just been relocated in a way… everything to do with the breast was still, it was all still part of me. And I just felt happier with that."* (0108 – Delayed DIEP)

Using one's own tissue for reconstruction appeared to be a highly motivating factor, demonstrating inherent value in autologous reconstruction, that seemed to be a reward in itself. The same participant gave further insight into the inherent value of the autologous reconstruction.

> *"it's replacing something that's missing and, to me, I felt it was worth the extra hours in surgery and the extra risk to have it all being as part of me. The fact that the tissue is mine and the blood vessels are mine and it's all part of my body."* (0108 – Delayed DIEP)

Autologous reconstruction helped alleviate the loss of the breast, and through descriptions such as "*it's part of me"*, there is the suggestion that it helps maintain a sense of the self. There is perhaps a link to the protection of identity, which may have been threatened during the breast cancer experience. Connections can be made to the other women (see section 4.4.2.2) who (sometimes laboriously) reconstructed their sense of self and femininity through their procedure. The connection to this maintenance of self is so meaningful, that such a reconstruction was worth the operative risk. This participant stressed that the significance of choosing this procedure was not due to the abdominoplasty.

> *"I know that a few women maybe opt for that one because they think oh I'll get a free tummy tuck as well but that really wasn't behind my decision… I knew I was never going to be svelte…. "* (0108 – Delayed DIEP)

She clearly distances herself from those that may have chosen a DIEP for a 'free tummy tuck', implying a negative view of cosmetic surgery, which is again suggestive of a moral discourse underlying breast-reconstruction decision-making.

The narratives of these women incorporated moral tropes concerning breast implants to describe their decision-making. Their narratives were often associated with how they saw themselves, in effect expressing the sort of person they were (their self-concept), which governed what they could accommodate in the reconstructed self, going forward. They used language such as good and bad, foreign and real, to articulate the rationale underpinning their decision-making. For these women, whose perspectives developed *The Real and Reconstituted Body*, just as breast implants were viewed as morally suspect, the converse perspective also held, namely that autologous procedures were intrinsically good, and demonstrated good character.

4.5.1.4 Summary of *Caring for the Body*

This section has introduced the different approaches to caring for the body that motivated choice of a particular type of reconstruction. Women were largely influenced by practical concerns, risk-based discourse, and personal preference for a 'natural' procedure. Practical concerns would often encourage implant-based reconstruction due to the reduced procedure duration, recovery time and follow up procedures. Many women had a personal preference for a natural reconstruction, which was associated intimately with choice of autologous procedure. Interestingly, choice of procedure guided by risk-based discourse appeared to follow the salience of the particular risk with the individual as opposed to objective measures of risk. It remains unclear whether women's approach to risk guided their choice of reconstruction, or whether risk perception was augmented in favour of, or used to defend, their initial preference. Perhaps different women choose either of these approaches. Finally, two distinct subgroups of women were identified. Women of the *Risk and Assaulted Body* subgroup prioritised the healthy body whilst radically reducing risk, whilst women of *The Real and Reconstituted Body* subgroup chose autologous reconstruction due to pejorative views of breast implants as morally inferior.

4.5.2 *The Influence of the Surgeon*

The second theme that influenced choice of type of reconstruction was entitled *The Influence of the Surgeon,* recognising the great role of the surgeon in decision-making. The relationship these women had with their surgeon held varying degrees of influence to the women in this study. However, of all the relationships that shaped choice, this was the most important, and frequently mentioned. The opinions and scope of practice of the surgeon seemed to be valued and influential when choosing a type of breast reconstruction. Most had positive views of their surgeons.

> *"Well I think you've got the number one surgeon there for a start. I personally would not choose anything any different to what I did when I chose and made the decision. And I don't think many people could sit here and say that."* (0105 – Immediate LD)

Many women had similar, glowing remarks, even where there were complications, or when outcomes were not perceived as ideal. This speaks to the powerful role of the relationship with the surgeon.

Many felt that the most important source of information for making their decision was their surgeon. Trust in the surgeon's opinion and authority was common:

> *"… they're the one that's going to do the operation so you've got to trust them and you need to feel that they're recommending the best option for you and that's what I thought with [surgeon]"* (0209 – Immediate IBR)

> *"You've always got a choice but you have to be guided by the medical experts. They see it all the time. They've got all the facts and figures and the scans and everything in front of them, so you know, at the end of the day, they know what's best for you. So, yeah."* (0206 – Delayed DIEP)

Trust in the surgeon was often linked to a confidence that the best (personalised) option has been recommended. This trust was described as a necessity. Although there is perhaps a slight difference in these accounts; the former suggests that the surgeon must convince the patient that the best reconstruction is being recommended, whilst the latter suggests that the doctor knows best. For others, trust was built through a sense of being comfortable.

> *"… the more I met [plastic surgeon], the more I felt happy to be in [surgeon's] hands. I felt really happy that it was [surgeon] that was doing it… it was quite important to me that [surgeon] – that I felt comfortable with [surgeon]."* (0104 – Delayed DIEP)

This trust in a surgeon could even result in a change of reconstructive choice, based on the surgeon's clinical advice:

> *"I think if we would have known for definite with just the biopsies that there was no other treatment going to be required, I'd have probably gone for the DIEP but [surgeon]… didn't want to risk it just in case and I'm thinking well we could just go for it and see what happens but, in hindsight, what [surgeon] recommended was the right thing to do."* (0205 – Immediate IBR)

In this case, this informant initially argued for a DIEP, however implant-based reconstruction was recommended by her surgeon as biopsies may have necessitated adjuvant therapy which could endanger autologous reconstruction. The site where this participant was treated offered the delayed-immediate approach and therefore IBR was a suitable interim measure for this woman.

Many of the participants appeared to go along with the advice or recommendation of their clinician, but in contrast one participant described a collaborative approach to decision-making. She described her role as making the 'big decisions' whilst the surgeon attended to the practical details of the reconstruction.

> *"I think it's making sure that people have as much information as possible and that, like I say, it isn't that sort of master and servant relationship, it's a collaborative thing…"*
>
> *"…so I made the decision I was like 'I want a mastectomy, I'm not going down the lumpectomy route, absolutely not' … so breast surgeons were still pushing for the lumpectomy even though I said 'I'm not doing it, not having it'" *repeated excerpt*
>
> *"…I went in there and I said 'this is what I want'... so I went in, sat down and said 'mastectomy and I want implant reconstruction'"*
>
> *"So the initial big decisions I made but then the little details since then so… putting the expanders in… how [surgeon's] going to kind of try and sort the symmetry out… So I think it's been collaborative..."* (0102 – Immediate IBR)

She did not subscribe to the historical subservient doctor-patient relationship in which there was complete deference for the surgeon's opinion. Although she describes it as a collaborative approach, her descriptions suggest that she was particularly proactive in choosing mastectomy against surgical advice for wide local excision ('lumpectomy'). Similarly, she advocated for immediate IBR despite undergoing radiotherapy (against surgical advice at Site 1 – see section 4.5.1.2.1).

Only one participant (0210) in this study described a negative experience with her surgeon. Despite this negative experience, which included reconstructive failure and change of surgeon, she still described the importance of the opinion of the reconstructive surgeon.

> *"… when a doctor recommends something and thinks that that's the best option and it would get rid of your cancer, I think you're probably more inclined to go 'yeah, just do it', which is what I did... because the recommendation was put there, I kind of thought that was my best option."*
>
> *"I think I am very inclined to listen to them because obviously they know best … Nobody was to know that my implant was going to react like this… I still feel that their recommendations were right... I think it would have been a much scarier place had I not have been given some type of lead from them"* (0210 – Immediate IBR)

There is perhaps the suggestion that for the patient, cancer care is entrusted to the clinician, and in return for this trust, expert advice is provided. Nonetheless, despite the importance of the reconstructive surgeon's opinion, this informant was not satisfied with the consultation. She elaborated:

> *"I don't feel I was given a choice to be honest. Whether that was because it was in such a traumatic situation[1], I don't know, but I wouldn't have gone against [surgeon's] recommendation either, I don't think. Now, if I was given that leaflet again for my other side, I would know I'd have a choice and I would have chosen the DIEP, but that's easy for me to say now, you know, so."* (0210 – Immediate IBR)
>
> [1] – referencing cancer diagnosis

From this account it did not seem this participant felt she had a choice, nor did she feel she could go against the surgeon's opinion. She suggests this may have been due to the emotional trauma of a cancer diagnosis. In the next extract, she also describes feeling rushed in the consultation.

> *"My surgeon, I didn't have a lot of time with, I felt quite rushed in my consultations with my surgeon. It's probably the main reason I swapped surgeons, to be honest, was I felt quite rushed in there, I felt my breast care nurses were amazing and had to intervene on a couple of occasions and say 'she's not getting what you're saying', because I think you're frightened… "* (0210 – Immediate IBR)

This discontent with the surgical consultation led to a change in surgeon, for her next reconstruction (she aimed for contralateral prophylactic mastectomy). The breakdown of the doctor-patient relationship appeared to be multifactorial in this case, due to rushed consultations and perception of lack of choice. The poor outcome may have also played a role in this, although other women still maintained strong relationships with their surgeon despite complications.

The previous passage is reminiscent of the evocative 'bunny in the headlight' statement (see section 4.4.3.1.1), in which another informant (0209) also felt rushed. She also relied heavily on the breast care nurses to improve understanding of the consultation with the surgeon, but instead spoke with them in follow up consultations.

> *"… I had numerous consultations with [the surgeon] and… I was very worried about, you know, my diagnosis… [the surgeon] sort of steered me in that way to say 'look, this is the best option for you, this is what I would do if I was you'"* (0209 – Immediate IBR)

Both of these women described choice being limited, or feeling that they were 'steered', towards implant-based reconstruction. Although in the case of participant 0209, any steering was recognised as based on clinical parameters related to inadequate amounts of skin and fat to achieve an optimal surgical outcome. It could be argued that the use of phrases such as 'this is what I would do if I was you' represent persuasive language, but as an expert, the surgeon will inevitably give an opinion in the best interest of the patient, likely with the intent of producing a better outcome. As this participant (0209) indicated that trust was vital, and despite the surgeon voicing their opinion of the optimal approach, she felt she was offered the best option. A critical point of difference between these two women was in their outcomes. One (0209) was satisfied with her chosen reconstruction and praised her surgeon whereas the other (0210) was not. So it is possible that the outcome may have adversely influenced recollection of the reconstructive consultation and perceptions of steering.

As a major subtheme described earlier (see section 4.5.1.2) explored how women perceived risk, it is worth commenting further on how women reported surgeons discussing risk with them. Earlier in this chapter certain risks or complications were discussed by women that concerned them most, or perceived as likely. However, there were accounts in which risk or complications were utilised by the surgeon, to explain why a procedure was unsuitable for them. With the introduction of the perception of 'steering' above, it must be considered that risk may also be used by surgeons as a negotiation tool in the reconstructive consultation. Notably, the absence of the communication of specific risks is also influential; one participant (0210) expressed discontent that complications such as implant failure weren't adequately discussed with her, which she which she unfortunately went on to experience.

In summary, the relationship with the surgeon was primarily one in which trust in the surgeon was considered important. For some participants, trust was a reflection of the respect associated with the role of the surgeon, not necessarily the person; contrastingly others indicated that trust unfolded through interaction, and was earned by demonstrations of empathy, listening to concerns, or through valuing the surgeon suggesting that they were presenting best reconstruction options. Two participants from Site 2 reported that their choice of type of reconstruction was directed (and restricted) by their surgeon. It was noted that other women changed their choice of type of reconstruction based on clinical advice from their surgeon. There are also likely instances in which surgeons will have described procedures in a way that would suggest a procedure, following which women may have had the perception of having made an independent choice.

4.6 Complex Reconstructive Journeys

Only two women in this study experienced what could be described as complex reconstruction journeys (0101, 0106). The complexity of these cases is in the multiple types or timings of reconstructions they had. Their inclusion adds value as maximum variation can be desirable when purposively sampling. Although their clinical journeys were not linear there were many commonalities in their experiences and these were shared with the other participants who had less complex clinical experiences. In fact, participant 0106's account played a vital role in the development of the *Real and Reconstituted Body* discourse (see section 4.5.2.3.1).

One participant (0101) who underwent contralateral prophylactic mastectomy (CPM) and bilateral LD reconstruction with implants, one side immediate and the other delayed, used the same language of normality in her decision-making (see section 4.4.2):

> *"I know it sounds really silly, I didn't want it to look like I'd got implants… I wanted it to look a little bit more natural and I think the fact of having muscle moved, I think that gave it a bit more of it's me kind of thing… There's more of me there than just a foreign -, I know I've got implants as well but there's a bit of me there as well. I don't know if I'm making sense but I know what I mean!"* (0101 – Immediate LD + Implant and Delayed LD + Implant)

Her decision-making is characterised by references to the *Preference for the Natural* and *The Real and Reconstituted Body* discourse. In this account she distances herself from the type of person who had implants, expressed the aim of reconstruction as a procedure that she perceived was natural, did not introduce anything 'foreign', and remained 'me' - although reconstituted. Clinical complexity necessitated compromises that impacted on her decision-making.

> *"… if I hadn't had the implants then it would have been, you know, hardly anything, it would have been so small that why bother going through the surgery kind of thing. So it was always, I didn't have enough fat on my back or enough, yeah, fat around the muscle to make an ample size"* (0101 – Immediate LD + Implant and Delayed LD + Implant)

Without breast implants the surgical outcome would be less favourable. particularly as her preference was for a 'natural cleavage' (see section 4.4.2.1). It is clear she was fully cognisant of her physiological limitations, that prevented her preferences being met; from her account, it appeared that she fully understood and could rationalise the decision-making.

> *"..[the LD] was more or less a foolproof kind of operation whereas the abdomen, you know, you've got a lot of things people go wrong, like you'll get a seroma … having the scar there … and the other thing was I think the time of recovery. The LD one seemed to be like a midway between just having just implants, which I couldn't have I know, but sort of like the simplest operation and the more complicated, it seemed to be a midway point, seemed to be the better of both worlds for me"* (0101 – Immediate LD + Implant and Delayed LD + Implant)

She compromised and took the 'midway' procedure. This description of a midway procedure was a repetition of the language used by the breast care nurses at that site (see section 5.3.2). For this participant, her choice appeared to be a function of her risk tolerance and her desire for a natural reconstruction; she did not have the same risk tolerance as most of the other women .

Overall, this participant's account suggests that the *Preference for the Natural* and *Perceptions of Risk* subthemes offer an understanding of how she determined her choice. This interpretive framework does offer some fit. Whilst not seeking to suggest that all women will engage in these approaches to *Caring for the Body,* they do seem to hold some coherence in relation to decision-making irrespective of whether straightforward or clinically complex.

4.7 Conclusion

This chapter has presented the themes that illuminate what influenced women when faced with having to make decisions regarding breast reconstruction. The chapter began by introducing the breast reconstruction decision-making experience of women, beginning with the experience of mastectomy. This was followed by the *Perceptions of Normal* that motivated reconstruction, and then the *Relationships Influencing Decision-Making.* The themes that influenced choice of type of reconstruction, the focus of this thesis, were then presented. These approaches were entitled *Caring for the Body*, which was comprised of three subthemes: *A Practical Decision, Perceptions of Risk* and *Preference for the Natural.* Women represented by *A Practical Decision* chose implant-based reconstruction in order to reduce any disruption of the operation on their personal lives. *Perceptions of Risk* was a central component to most women's decision-making, with women seemingly focusing on the specific risk that held the most salience to them; risk perception appeared to be enhanced for these risks. The final subtheme was entitled *Preference for the Natural,* which represented a group of women who had an increased tolerance for risk, and preferred a more complex reconstruction in tissue based procedures. The second theme was called *The Influence of the Surgeon* and described the most influential relationship in women's decision-making. It was predominately a relationship of trust and could direct choice of type of breast reconstruction. The next chapter describes the analysis of the clinicians interviewed in this study (Chapter 5) where the concepts of trust and influence of the clinician is explored further.

CHAPTER 5 – CLINICIAN RESULTS

5.1 Introduction

This chapter presents the findings and analysis of the interviews undertaken with the clinicians recruited to this study. Their experiences of breast reconstruction consultations were explored, focusing on what women find most influential when choosing a type of breast reconstruction. This chapter follows the same structure as Chapter 4, beginning with an overview of the participant characteristics and reflection on the sampling approach. The themes developed from the interview data will then be presented, using excerpts to represent participant accounts. Again, a generic qualitative approach adopting a pragmatic interpretive framework was used for analysis.

5.2 Overview of Participant Characteristics

This study was enriched by eliciting and comparing the perspectives of patients and clinicians, with successful recruitment of four consultants and two breast care nurses. The recruitment strategy represented a convenience sample and all types of clinicians intended for sampling were recruited. All the study participants were known to me before the time of recruitment. Breast care nurses were recruited solely from the first site, as there was a lack of significant interest in participation from nurses at the second site (BCNs from Site 1 were my colleagues but I was not familiar with the BCNs at Site 2). Attempts were made to recruit clinicians not previously known to me, also without success, suggesting that my professional relationship may have encouraged successful recruitment.

Participant characteristics are summarised below in Table 5.1. As the breast reconstruction community is not particularly large, further participant characteristics could not be divulged, to protect confidentiality. For this reason, clinicians will often be referred to as ‘they’, as disclosure of gender could also compromise anonymity. Interviews lasted on average 50 minutes, with an average of 54 minutes for the breast care nurses and 48 minutes for the surgeons. Both breast care nurses opted for face to face interviews, whilst all consultants chose telephone interviews. Site characteristics remain the same as discussed in Chapter 4 (see section 4.3).

Table 5. 1 – Clinician Participant Characteristics

Participant	Site	Role	Interview
C101	1	Breast Care Nurse	Face to Face
C102	1	Consultant – Oncoplastic Breast Surgeon	Telephone
C103	1	Breast Care Nurse	Face to Face
C104	1	Consultant – Plastic Surgeon	Telephone
C201	2	Consultant – Oncoplastic Breast Surgeon	Telephone
C202	2	Consultant – Oncoplastic Breast Surgeon	Telephone

5.3 Themes

Analysis of the data explored the clinician perspective of what was influential when women chose a type of breast reconstruction, identifying three major themes. The first was that of *Trust*, which represents the role of women's trust in the surgeon as a primary influencing factor in the decision-making process. A subtheme of *Trust,* entitled *A Patient Centred Approach,* elaborated on the patient-centred approach that surgeons believed contributed to the development of trust. The second theme was entitled *The Clinician's Preference*, which explores how surgeons' training and experience affects the way they deliver the breast reconstruction consultation. The third theme developed was *Clinical Restrictions on Choice*, which describes clinical attributes of women and procedures that restrict choice during the decision-making process. The themes were clearly different from those developed from the interviews with the women, as described in Chapter 4. There was however an area of overlap, recognising the great influence of the surgeon. A comparison of the findings is offered later in this chapter (see section 5.4).

5.3.1 *Trust*

The results from Chapter 4 introduced the value women placed in the opinion of their surgeon. Indeed, the surgeons also believed in the importance of their opinion and relationship with their patients. Perhaps the most striking finding is that when asked what is most influential to women when choosing a type of breast reconstruction, two surgeons responded that it was in fact the surgeon who inspires confidence in a choice.

> *"The single most important if I had to choose on the single most important is what confidence the surgeon inspires in them in favouring …"* (C104 – PS)
>
> *"… obviously I think a big part of what influences a patient is their surgeon. I think that plays a very big part in the decision making because patients, especially patients who have not come in informed or who have not had much exposure to that, they will be guided by the surgeon."* (C102 – OPBS)

The surgeon C104 went on to describe the deciding clinical factors that clinicians consider, such as clinical assessment, the patient as a person, as well as the surgeon's own experience and expertise. These are balanced against each other, the result of which yields the favoured option. The same surgeon expanded:

> *"… the moment the patient has faith and has taken with faith and has quizzed and has answers and has confidence in the choice that the surgeon is favouring, I think this will be their most important parameter in choosing the reconstruction, the faith and the confidence they will put in what the surgeon is presenting to them."* (C104 – PS)

In this account, the patient must both have faith and confidence in the choice presented as optimal by the surgeon, and unlike faith, confidence is earned by holding up to the woman's questioning. This was echoed by a surgeon at the second site.

> *"So for some patients actually they place a lot of trust in the surgeon and would rather they make the decision. For some patients they do respect the surgeon's opinion, but they actually want to see that the surgeon can provide a rational argument as to why they think that option is better than the other. So I think the surgeon's opinion is always very important to all patients…"* (C202 – OPBS)

This surgeon however distinguishes between patients who prefer to follow the reasoning behind the surgeon's opinion, and those who prefer the surgeon to make the decision, which are recognised areas on the spectrum of shared decision-making (Clayman et al, 2012).

This theme represents an area of agreement with the women recruited to this study. Trust in the clinician has been found to be important in cancer care, more so than in other serious illnesses (Hillen et al 2011, Mechanic and Meyer 2000). All four consultants recruited to this study recognised their influential role in the decision-making process. Some of the surgeons felt that this trust was built when their opinion was defended rationally against questioning by their patients, however others suggested that trust could occur even without questioning. The development of trust in the surgeon was the most influential factor for two clinicians, who believed it guided the choice of breast reconstruction modality in women. Trust in medical professionals is underpinned primarily by the concept of interpersonal competence (Rottmann et al, 2010), and also influenced by competence in medical knowledge (Bakker et al 2001). It can be developed when a patient feels that their doctor cares, respects them, and makes an effort to provide an individualised service (Rottmann et al 2010), reminiscent of patient-centred care models (see section 1.5.2). This explanation of how trust is developed appeared to be reflected in the approach by surgeons, and contributed to the development of the subtheme below.

5.3.1.1 *A Patient-Centred Approach*

Strongly linked to the development of trust in the doctor-patient relationship, was the clinicians' pursuit of a *Patient-Centred Approach*. It explored the techniques employed by surgeons to build the trusting relationship that was so influential in the decision-making process. The surgeons recruited to this study spoke at length about various components of a patient-centred approach.

The two major dimensions of newer models of patient-centred care (see section 1.5.2) were often alluded to by participants. All surgeons took an active interest in understanding the patient as an individual, the first major dimension.

> *"… I do ask consistently about family requirements, the social work requirements, time to return to work, time they can afford off work, how they see the future ... For example … needing time to rest from say heavy lifting or using their arm again would be a very important issue for a lady who had an eight month old baby for example or has a household where she's the sole breadwinner for, I don't know, very young children or who has to care for a disabled child and need a lot of handling, so the family and personal requirements I think play a big role."* (C104 – PS)

They would often present case examples to represent common streams of decision-making based on women's personal circumstances, which they all addressed. Some (C102, C104) also disclosed aspects of the second major dimension of newer models of patient-centred care, the doctor-patient relationship, which included sharing power and responsibility.

> *"I don't think patients should be swayed per se unless it's for good clinical reasons, you know, in other words, for example an autologous reconstruction would be too risky, you know, and I wouldn't necessarily even say 'you can't have that operation', I would say that these are the risks and these risks far outweigh risks of another type of reconstruction, but the patient ultimately has -, it's a dialogue, it's a decision that is made together with the patient, it's not for the patient."* (C102 – OPBS)

In particular, C102 (OPBS) frequently expressed the values of patient-centred care and shared decision-making.

Central to this was the provision of correct and objective information to women. All clinicians felt they needed to address women's existing knowledge of breast reconstruction.

> *"…breast reconstruction is very common, nowadays and the majority of patients come having had a relative, a friend, someone at work and their initial bias when they're going to make a decision on reconstruction is what they know from either contact or what's in internet but I think that's where we step in and influence their decision with objective information, so I think that is a very important factor, the final decision is based on objective information and informed consent"* (C201 – OPBS)

They discussed women's existing understanding of breast reconstruction, and how to appropriately manage this – a key aspect of shared decision-making. Given the difference in women's pre-existing knowledge, they would respond to individual women's needs and wishes:

> *"…so I think it's a key point you know [that] informed consent [is] very objective and having offered all sources of information that are channelled towards the individual needs."* (C201 – OPBS)

> *"So I tailor the level of information and even the minutiae of information based on patients' wishes as well."* (C202 – OPBS)

Whilst all surgeons reported tailoring and individualising information provision, some were also very flexible, providing further consultations as required by the individual:

> *"I think the most important thing is putting things in perspective for patients and giving them sufficient time to digest all the information and to be able to make a decision*

> *that is right for them and being able to perhaps come and talk to you on several occasions… some patients need one or two consultations… and some patients need more time and I think you've got to have a more tailored approach, yeah."* (C102 – OPBS)

Giving women the right amount of time to women was described by most clinicians, with one estimating that women received 2.5 to 3 hours of contact over a variety of consultations, excluding time spent with BCNs (C202).

An important element of the informed consent process was recognition of its link to higher quality decisions and post-operative satisfaction, even when outcomes are not ideal.

> *"…we have a very good satisfaction rate reported to us in clinic with our patients… And that's even the case when perhaps the reconstruction result is not what I would look at as ideal, and I think it's because… part of that patient perspective and perception is moulded by the pre-op consultations. If you paint a picture, a very honest picture of what it may look like and they achieved that, patients are satisfied…"* (C202 – OPBS)

> *"But ultimately, the best reconstruction is the one that the patient has chosen knowing fully what to expect and not being unpleasantly surprised or finding herself in a difficult position in the future with things she had not been told or she was not expecting might happen… if she had consciously chosen what was being offered, it's still a good reconstruction for her in my opinion."* (C104 – PS)

There is also the suggestion by C104 (PS) that an informed decision was a high quality (or 'best') decision, even if it is not the option recommended by the surgeon.

> *"You know, I think reconstruction is about doing the right operation for the right patient."* (C102 – OPBS)

> *"And it's a balance about treating the cancer but also getting the right operation for the right patient."* (C202 – OPBS)

These descriptions of clinicians aspiring to a patient-centred approach generally suggest that they try to identify women's preference of reconstruction, and encourage women to make what is the best decision for them.

A patient-centred consultation was described by all surgeons as a discussion giving the best possible support for women's decision-making. Informed consent (which also improved patient satisfaction), tailored information provision, increased flexibility in follow-ups and recognition of patient preference were integral to this technique. These aspects of the consultation were thought to promote the development of trust, but also encourage high-quality decision-making. There was however some tension in the way these clinicians approached patient-centredness, as they included some weighted descriptions of procedures, and even expressed a reconstructive preference (see section 5.3.2 below).

5.3.2 *The Clinician's Preference*

Perhaps difficult to reconcile with the pursuit of a patient-centred approach were descriptions of clinician preference. *The Clinician's Preference* was a second, contrasting theme developed from the clinician interviews. All the recruited surgeons mentioned that they either offered or performed a full repertoire of procedures, which usually included IBR and autologous flaps. Two of the four surgeons (C102 and C202) were quite clear that they offered all these procedures equally.

> *"I'm not partial to a type of reconstruction. I'm not partial to the only types of reconstruction I do."*
>
> *"…we don't offer free flaps in our unit anymore but that doesn't mean that I'm less likely to recommend a free flap abdominal form of reconstruction to my patients."* (C102 – OPBS)
>
> *"So I present all of them [types of reconstruction] equally unless there are particular patient factors ... I mean one can talk ideologically about what the best reconstruction option would be, but we don't have that ideal at the moment."* (C202 – OPBS)

These surgeons held no personal preference with regard to reconstructive type, and were happy to refer women onwards for reconstructions that they did not provide, when appropriate. For example, recommending a free flap to a woman would require referral to a plastic surgeon. Neither said that they believed that any reconstruction modality was the best.

Despite this, all four surgeons talked about a degree of what one surgeon termed 'bias' (C202). They either agreed that surgeons in general influenced patient preference, or expressed a preference themselves. One surgeon, who also did not express a personal preference, thought it to be natural, in part due to knowledge of personal ability, experience and outcomes.

> *"… I think that [referencing 'bias' in surgeons] naturally probably does occur because you know what your outcomes and results are, you know what you would expect if you*

> *were to undertake that strategy, or have an idea what you'd expect for that individual patient, and that may be different for different surgeons, based on experience, expertise, different consumables, different techniques. So there is an element of bias to how you present the strategy… "* (C202 - OPBS)

This account suggests bias in a subtle, perhaps inadvertent fashion, that the option that the surgeon feels they can perform best, will naturally be presented as best, or communicated in the best way.

> *"…we as surgeons inform our patients and guide our patients makes a huge impact on patients and that's why sometimes I think in certain units you see a certain trend, you know, it must be related in somehow to the consultation or to the information giving because otherwise, you know, why would that pattern develop."* (C102 - OPBS)

This surgeon proposed, from personal experience, that local trends developed due to the way options are communicated by surgeons. As previously, this surgeon did not express a personal preference and seemed to espouse the ideals of patient-centeredness. However, this surgeon's experience of local trend development was suggested by other participant accounts.

Site Specific Culture – Site 1

Care must be taken when drawing conclusions across a site from a small convenience sample. However, findings may point toward a different 'reconstructive culture' at each site (see section 4.3 for site characteristics). This appeared to be more prominent at Site 1, where prior to C102 (OPBS) recently joining, two plastic surgeons were in practice. Plastic surgeons typically provide a full range of reconstructions, including free flap reconstruction. In keeping with the procedures they had specialised to perform, autologous reconstruction appeared to be favoured by at least one of these surgeons.

> *"I would always favour an autologous reconstruction based on my experience in providing what I think is best in my hands and my experience with a long term future of the patient and the reconstruction"* (C104 – PS)

The reasoning for this preference at first seems practical, describing that technical ability and experience contributed to this preference. However, this surgeon also believed that autologous reconstruction was the ideal.

> *"…I believe that reconstruction of all parts of the human body should be same for same or we should strive for same for same. And autologous tissue reconstruction … I can say it from experience, but mostly I have been trained to believe that it is the most natural and appropriate reconstruction for all parts of the human body, including the breast. "*
>
> *"… plastic surgery training revolves around, it's about reconstruction, that's why the title plastic and reconstructive surgeon is, so it's same for same. And before the advent of prosthetic and silicone, all the plastic surgeons historically in Britain and in other countries have been striving to find same for same methods for reconstructing the human body."* (C104 - PS)

The definition of autologous reconstruction defined as 'most natural and appropriate' suggests a deep belief in this type of reconstruction. The surgeon explicitly attributes this ethos to the training of plastic surgeons in Britain, and suggests that plastic surgeons in other countries would have a similar view.

This belief in autologous reconstruction was clearly expressed in the way surgeon C104 described the reconstructive consultation.

> *"So people often feel that the shorter the surgery, the quicker the recovery, the lesser the scars, the quicker I'm at home, the better it is… these tick boxes if you want, are usually being ticked by prosthetic non-autologous reconstructions, here is my role I think to let them know that … you need to envisage how the future will be, because I have seen a revision on procedures, I have seen failure of implant reconstructions after crippling months or years of complications such as capsular contracture or asymmetry or discomfort and I've seen those patients coming a circle back again and asking for an autologous reconstruction... And I try to give them a view of the future because I have seen the future…"* (C104 – PS)

The surgeon provided an emotive description of implant based reconstruction, which contained persuasive descriptions, such as 'failure' and 'crippling', that would likely engender negative views of breast implants to the typical woman. Despite this statement, this surgeon also described aspects of a patient-centred approach, which is not in keeping with this weighted presentation of options.

Breast care nurses at Site 1 similarly preferred autologous procedures. When asked what the ideal reconstruction was, one of the nurses replied:

> *"Probably using your own tissue… an implant's not for life, you can have lots of problems, it doesn't look as real, it doesn't grow with you, and, if you're a younger woman, then you've got to think of that for all your life… using your own tissue gives a much nicer, natural cosmetic result."* (C101 - BCN)

Notably, the language utilised by this breast care nurse was very much a reflection of the language used by the women in Chapter 4. The use of words that imply value, such as 'real' and 'natural', was suggestive of a similar moral discourse to that which guided the decision-making of the women represented by *The Real and Reconstituted Body* subtheme. The reflection of the language used by women patients may represent a form of mirroring, which is frequently taught in medical and nursing school.

In particular, the same breast care nurse at Site 1 (C101) may have favoured the latissimus dorsi breast reconstruction.

> *"Maybe because of people's general health, that they can't have the DIEP. It's a much bigger surgery. The risks are higher… Implants don't give the nicest, best cosmetic results, so if patients are offered these choices, the LD is the middle one. It's much, much better using your own tissue, but it's not such big surgery as a DIEP, and the risks of loss are less. So I think probably, yeah, the LDs would be the most popular. "* (C101 – BCN)

The other breast care nurse at Site 1 (C103) disclosed a personal preference for the DIEP, which appeared rooted in previous experience at a renowned plastic surgery hospital in the UK, which frequently performed DIEPs as the 'gold standard' procedure. However, both believed that the LD was the most commonly performed procedure at Site 1, which raises the possibility that a site specific culture could be driving local trends.

> *"… in my limited thinking, I would probably say LD flaps are probably done more."* (C101 – BCN)

> *"I would say probably LD flap reconstruction is one of the most common one in this department, because… it is in the middle. Because with implant based reconstruction yes, there is quicker recovery but in the long term the patient come across more problem, and a lot of people are not interested in having, as soon as they hear the name of implant they don't want to consider that one because they think it's a foreign body and then it's got a shelf life so they are not interested. Yes they like to have a tissue from their, obviously, some part of the body, but considering obviously recovery time, risk of complication, flap fail, and then what co-morbidity they have, it might be like DIEP flap, it will be too much for them."* (C103 – BCN)

Notably, both BCNs viewed the LD as a 'middle' type of procedure, holding the benefits of autologous reconstruction without the degree of risk and invasiveness of the DIEP. This is reminiscent of the account of a woman from Site 1, who used similar phrasing when discussing the procedure. Although the LD was described as the most popular reconstruction at this site, the LD is increasingly viewed as a salvage procedure as opposed to a type of primary breast reconstruction, with reducing frequency of use in the UK (see section 1.6).

Site Specific Culture – Site 2

It is worth reiterating that care must be taken when drawing conclusions from a small convenience sample. However, findings could point toward a different site specific culture at Site 2, which employed four OPBSs (see section 4.3), two of whom were interviewed. The views of C202 (OPBS) have been discussed above, suggesting a natural 'bias' in the communication of an option, towards the one which the surgeon feels they can perform best. The other surgeon at Site 2 also described presenting options objectively, guiding, and not giving preferences without a reason.

> *"…what I never try to do is give them my preference without any reasoning, you know because as far as I'm concerned if I offer all reconstruction options you know I need to present it in an objective way but at the same time if I'm the expert I need to guide them is there any factors that could mean one procedure may be better for them than others if you know what I mean, so I'm there to advise them but not to express a preference"* (C201 – OPBS)

However, this surgeon recognised that their practice could be perceived as preferring implant-based reconstruction over DIEP.

> *"…the impression what you could get from the outside is that I may even like implant breast reconstruction when earlier on they seemed to be make it very clear that the gold standard is autologous particularly the DIEP flap constructions but if I use [more] implants it's because of the worrying about future radiotherapy damaging your immediate reconstruction and I've been using the yeah, immediate delayed or delayed immediate approach for a very long time yes, yes."* (C201 - OPBS)

The surgeon attributed this perceived preference to the delayed-immediate approach (see section 1.3.2), which appeared to be ingrained in their practice. They argued that preference for usage of implants was primarily to prevent future radiotherapy causing damage to the immediate reconstruction. These entries suggest that this surgeon may have guided women to the procedure that they viewed as best for them. The frequency with which this occurred however, was unusually high.

> *"… we see probably in and around perhaps ninety percent of our reconstructions being implant based which actually is very similar to the national trend…"* (C202 – OPBS)

Mennie et al (2017) however suggested that IBR in the UK accounts for between 17-68% of immediate reconstructions (range between different cancer networks), and delayed IBR, roughly 25%. This unusually high rate of implant-based reconstruction at this site suggests that there may be a degree of reconstruction preference, or perhaps better described as the reconstruction that these surgeons felt would provide the best clinical outcome for their patients.

> *"…this is the reason I examine the patients first and I don't want to tell them what the gold standard is before I've examined them because they may not be suitable and have no tissue in their abdomen, they may not be suitable because they're smokers or obese, they may not want it, so I try to have a personalised approach…"* (C201 – OBPS)
>
> *"So there is evidence around long term satisfaction of patients with reconstruction and quite often the autologous reconstruction options, particularly the DIEP reconstruction fares better. But I think that doesn't quite translate into saying that's the best reconstructive option because it's what's right for each patient. An individual patient may not wish to have such a complex operation to start with or have abdominal scars. So actually it depends what you're looking as your outcome and what your outcomes measures you're dealing with, but also how the patients are at the time."* (C202 – OBPS)

In keeping with the possible degree of preference for IBR, the accounts from the surgeons at Site 2 suggested a guarded view of the 'gold standard' DIEP breast reconstruction.

Despite the earlier statements of these surgeons, suggesting a lack of preference and provision of objective information, they still guided women, and may have contributed to the development of a local trend. C202's earlier statement is important; they proposed that surgeons have a natural 'bias' towards the procedure that they provide the best, suggesting that it may be inadvertently communicated. It is recognised that non-verbal cues, which are so important in communication, may give more weight to particular options that appear balanced in a transcript. Also, language may be persuasive without overtly expressing a preference. These may be responsible for the perception of providing objective information, whilst still influencing choice. Merely the ordering and perceived weight given to information could influence decision-making. Surgeons may also not be completely cognisant of non-verbal cues that suggest a better or preferred option; or they may not disclose any preference in an interview.

To conclude, a central finding of this study was the suggestion of preference by two of the participating surgeons. One stated their preference, whilst for another, it was implicit. The reason for such preference was variable, however they included British plastic surgical training and the preservation of the integrity of immediate reconstructions. Preference of surgeons for certain reconstructive procedures has been reported in the literature (Potter et al, 2013 – see section 2.3.5). Given the first influential factor of *Trust,* and the second of *The Clinician's Preference,* it is could indicate that together these factors can drive trends towards specific procedural types within certain breast reconstruction units, which is suggested by these findings. The importance of language and non-verbal cues in the consultation has been introduced. The BCNs at Site 1 appeared to share the same reconstructive inclination as the surgeons at that site, whilst also utilising the same language as women. In keeping with the importance of language, this is discussed further in Chapter 6 (see section 6.8).

5.3.3 *Clinical Restrictions on Choice*

The final theme developed was entitled *Clinical Restrictions on Choice* which were discussed much more frequently by the clinicians than the women who were interviewed.

Radiotherapy

One of the major clinical restrictions of choice was the requirement for radiotherapy. Women from Site 1 of this study discussed radiotherapy as a reason for not being offered immediate reconstruction. This was confirmed by the clinicians at Site 1.

> *"…there was a very firm sort of trend to not offer patients who need radiotherapy immediate reconstruction. And that was upheld by the reconstruction service that was in place."* (C102 – OPBS)

> *"But I don't think that surgeons here are really keen to offer [immediate reconstruction in the context of radiotherapy] to a patient … even if the people have had the radiotherapy, they try to leave it a year before actual reconstruction because they think*

> *that again the effect on their skin and the complication after reconstruction will be more…"* (C103 - BCN)

At Site 2 however, immediate reconstruction was not excluded due to radiotherapy.

> *"[Radiotherapy] doesn't exclude implant based surgery for me, because we have a use of a polyurethane implant which with our current series does seem to confer an advantage on capsular contracture rates following radiotherapy, so it is an option I do offer to patients, bearing in mind there still is a slightly higher capsular contracture rate with it, but it doesn't exclude it as an absolute contraindication."* (C202 – OPBS)

The polyurethane implant utilised at Site 2 was associated with advantageous rates of capsular contracture following radiotherapy (see section 1.3.1). C201's statements in the previous section suggest that they may have been an early adopter of the delayed-immediate approach at this site (supported elsewhere in the transcript), which may imply an ethos of applying newer techniques, compared to Site 1. This surgeon also described radiotherapy in the delayed-immediate approach.

> *"So if patients are needing adjuvant treatment I will try to talk to them about why one might want to go for the more simpler or least complex option, perhaps as a bridge to their final reconstruction or actually of their definitive reconstruction."* (C202 - OPBS)

At Site 2, radiotherapy primarily excluded only the DIEP flap.

> *"So radiotherapy only excludes DIEP reconstructions really in the immediate setting if it is likely, but otherwise it is discussed with its relative merits and potential complications on any reconstruction should the patient be likely to need radiotherapy."* (C202 – OPBS)

Typical practice at Site 1 and Site 2 differed considerably with regard to practice in the context of radiotherapy (see section 4.3).

Clinicians from Site 1 however did describe situations in which they would offer reconstruction in the context of radiotherapy.

> *"My practice is slightly different… I wouldn't say that I would recommend immediate reconstruction for all patients who need radiotherapy, but I would not exclude patients who need radiotherapy from immediate reconstruction and I have certainly, you know, operated on patients who are known to need radiotherapy before their reconstruction…"* (C102 – OPBS)

This surgeon mentioned indications in which radiotherapy would be required before reconstruction, such as women with large breast tumours. They reported that women had not done badly when their reconstructions were irradiated, and that as long as the woman was informed, it would be acceptable to take this risk. However, they stressed that this must be undertaken cautiously, as breakdown of a reconstruction due to radiotherapy can delay further breast cancer treatment, such as chemotherapy. The other surgeon from the first site described quite different views regarding reconstructions and radiotherapy, compared to surgeons from Site 2.

> *"I have traditionally been brought up with always favouring reconstruction after the radiotherapy has been completed... If… I expect that there is going to be radiotherapy but it's in the best interest of this patient to have the reconstruction now rather than leave with the morbidity of not having a reconstruction for eighteen months … In these circumstances I will choose an immediate reconstruction with an autologous flap, no prosthetic material."* (C104 - PS)

Both surgeons from the first site described their practice as generally attempting to avoid immediate reconstruction in patients who will undergo radiotherapy, however they had specific, quite patient-centred reasons for allowing exceptions to their practice. But, in contrast to the practice of the surgeons at the second site, the plastic surgeon avoided use of breast implants when a reconstruction was likely to be irradiated. There is clearly a difference in opinion between sites on the type of reconstruction that occurs if radiotherapy is indicated, as the surgeons at Site 2 viewed radiotherapy as an exclusion criterion for autologous reconstruction. This could perhaps be driven in part by the preference for autologous reconstruction expressed by C104.

Breast reconstruction decision-making in the context of radiotherapy is complex. Differing preferences were described by clinicians at the two sites regarding provision of immediate reconstruction when radiotherapy is known to be required. There were also differing preferences regarding the type of reconstruction that can be irradiated.

Other Risk Factors

An important clinical restriction of choice included suitable physical characteristics (see section 1.3.1). C201 (OPBS) previously reported difficulty in telling women that the DIEP flap is the gold standard, as many are not suitable for it. One of these reasons included lack of sufficient abdominal tissue to relocate in order to reconstruct a breast. Conversely, too much fatty issue, when women are obese, represented a contraindication to a DIEP flap.

Obesity and smoking were common risk factors that restricted choice, particularly mentioned by C201 (OPBS). These clinical factors were rarely mentioned by the women in the previous chapter, but were more frequently discussed by the clinicians. This surgeon did describe how some women are given the chance to optimise their comorbidities (for example lose weight, or stop smoking) if a procedure such as a DIEP is desired, particularly in the delayed setting, but in general explained that smoking and obesity would preclude a DIEP reconstruction in practice.

> *"…you know in my practice smokers do not get a DIEP flap, if they're not extremely heavy smokers they can have an implant in the immediate setting, not in the delay … the same with BMI's up to 32/35 you know, we I accept pushing the boundaries to that point with immediate breast reconstruction not with delayed or revision reconstruction …"*(C201 - OPBS)

This oncoplastic surgeon also describes a grading of cigarette consumption, in that 'not extremely heavy' smokers can have immediate implant reconstruction (as they would have had an anaesthetic to have a mastectomy anyways). Similar gradings with BMIs were described, with some allowance for higher BMIs in the case of immediate reconstructions as well. The other oncoplastic surgeon at that site explained how the high volume of IBR at the second site was partly driven by women not being eligible for other procedures.

> *"…I think part of that reflects the low complexity of that procedure, part of that reflects … patient related factors as well as choice, not choosing the other options… partly governed by the fact the patient's not eligible for the others…"* (C202 - OPBS)

Not being eligible for other procedures could indicate requirement for radiotherapy, risk factors as well as lack of sufficient abdominal tissue. However, as the local population had high rates of significant comorbidities (see section 4.3), this may have contributed to higher rates of implant-based reconstruction at this site.

This theme represents an important selection of clinical restrictions that directly influenced women when choosing to have a type of breast reconstruction. These included radiotherapy, physical characteristics and risk factors. Surgeons appeared to make trade-offs to help women achieve reconstruction, for example pushing the range of acceptable BMI in immediate reconstruction, and accommodating immediate reconstruction with radiotherapy when it was felt it would significantly benefit their patient. Apart from radiotherapy, these did not frequently appear in the women's interviews.

5.4 Comparison to Results from Interviews with Women

Although care must be taken when drawing conclusions from a small convenience sample of clinicians, the themes described in Chapter 4 differ considerably from those developed through analysis of the clinician interviews. The only area of overlap was the agreement regarding the great influence of the surgeon. The themes developed from these clinicians' accounts seemed to be more reflective of what a surgeon or clinician would think as influential, as opposed to what women found influential when choosing a type of reconstruction.

Nonetheless, clinicians clearly recognised and described common decision-making patterns. For example, women's desire for natural reconstructions, linked to autologous reconstruction, were noted by all clinicians in this study. Young mothers requiring functionality and a reduced recovery time were frequently mentioned, likely linked to choice of IBR. Women did discuss some of the clinical restrictions of choice, however they were much more pronounced in the interviews with the surgeons.

There was a broad understanding of women's motivations when choosing to have breast reconstruction, but limited discussion and recognition of individual value systems. This is best explained by the following excerpt.

> *"So I think patients would ideally wish for a reconstruction that gives them a natural shape, a natural feel, a reconstruction that has low complication rates, a reconstruction that is simple or less complex, with a reduced recovery and back to normal functionality thereafter, and a reconstruction that is stable over time... we do not have a reconstruction that fits all of those categories and all of those ideals, so therefore patients make a choice and always compromises to some extent about each of those to find out then what they will ultimately choose."* (C202 - OPBS)

The description of OPBS C202 seems to revolve around a notion in which all patients compromise to some extent. Although this interpretation of what is important to women when choosing a type of breast reconstruction can explain the merits of the procedures themselves, it does not seem to take into account the values of the women presented in Chapter 4, who rarely mentioned compromise (only by participant 0101). For example, the women of the *Preference for the Natural* were not overly concerned with procedural complexity, complication rates (apart those associated with breast implants) and recovery periods in their quest to achieve a natural reconstruction. Perhaps even the arduous nature of the journey, suggested by procedural complexity, was linked to an improved self-concept for some of the women of *The Real and Reconstituted Body*. Conversely, women represented by *A Practical Decision* did not disclose any desire for a naturally shaped or natural feeling reconstruction. In order for clinicians to support women in the decision-making process, which is based in part on personal values (as established in the last chapter), they must first understand the women with whom they take the reconstructive journey.

Another major point of discussion between the women and clinicians is the approach to risk. As demonstrated in the last chapter, women's approach to overall risk, and the salience of particular risks, were distinct influencing factors in determining their preference for a type of reconstruction. Clinicians did not explicitly describe how they communicated risk to women, apart from vague mention of leaflets. It was however noted that clinicians seemed to communicate particular risks that may have encouraged choice of the preferred procedure at each site. For example, C104 highlighted 'crippling' implant failure risks whilst C201 favoured the delayed-immediate approach to reduce the risk of radiation to autologous reconstructions, or restricted choice to autologous procedures for smokers and women of raised BMI. In the last chapter (see section 4.5.1.2), some women from Site 2 who expressed concern for reconstructive flap failure chose implant-based reconstruction, although risk of failure was significantly higher in immediate IBR versus DIEP. Coupled with C202's statement that 90% of reconstructions performed at Site 2 are IBR, it can be inferred that risk communication at this site may have been atypical. Similarly, with evidence of weighted descriptions of risk in favour of autologous reconstruction at Site 1, and the preponderance of LD reconstructions at this site (out of keeping with modern clinical practice), it suggests that there may have been atypical risk communication at this site as well.

Accurate communication of risk is a central aspect of shared decision-making, but clinicians should also be cognisant of how women perceive risk. Risk perception was not referenced at all by the clinicians. This absence is critical, as women clearly perceived risk very differently, and this was a particular influence of type of reconstruction. An important element of risk perception presented in Chapter 4 was the heightened concern for cancer recurrence, linked to CPM at Site 2 (acknowledging that the sample of women was not a statistically representative one); this was also not recognised by clinicians.

A comparison of clinicians' views and women's views can also be made in the approach to shared decision-making. One surgeon thought that women generally preferred to follow the surgeon's opinion once reasoning is provided for it, or preferred that the surgeon make the decision. Women however reported their decision-making differently. Some had clear opinions of what they wanted and some collaborated with the surgeons. But the only two women from this study who described experiences of 'steering' from the surgeon appeared too stunned to argue (or know) their preference. One of these women's excerpts is compared to a clinician's, both of which are repeated for comparison.

> *"I'd never looked at breast reconstruction before and so when a doctor recommends something and thinks that that's the best option and it would get rid of your cancer, I think you're probably more inclined to go 'yeah, just do it', which is what I did."* (0210 – Immediate IBR)
>
> *"…well obviously I think a big part of what influences a patient is their surgeon. I think that plays a very big part in the decision making because patients, especially patients who have not come in informed or who have not had much exposure to that, they will be guided by the surgeon… "* (C102 – OPBS)

A part of being 'steered' by the surgeon appeared to be linked to women who had no experience or exposure to breast reconstruction. These two women also noted the speed of their consultations, which often required interjection from their breast care nurses (0210), either to ask the surgeon to slow down, or to reiterate the contents of the consultation. This appeared at odds with the general approach of the clinicians interviewed, as they appeared to place importance in giving women the appropriate amount of time for decision-making, based on individual need.

One of the most important findings from these interviews was the suggestion that particular, or weighted, language in the consultation may have influenced some women's choice of reconstruction, in the absence of an overtly stated preference. A similar language in the description of LD reconstructions was utilised by both BCNs and a woman in the last chapter (0101). Furthermore, the language used by one of the BCNs was a reflection of the same words that the women of *Preference for the Natural* expressed, whilst also disclosing a preference for LD reconstructions. The belief in autologous reconstruction expressed by C104 (PS) was presented persuasively, but not similarly to the women of *Preference for the Natural.* Although the adoption of language doesn't necessarily entail adoption of reconstructive choice, words do express the concepts they present (Lakoff and Johnson, 1980). This use of language is a point of interest and discussed further in the next chapter.

5.5 Summary

The views of clinicians about women's choices of reconstruction have been explored in this chapter. Three themes were developed, which identified factors that clinicians believed influenced women when choosing a type of breast reconstruction. The first, entitled *Trust,* represented the great influence of the surgeon in reconstructive decision-making, which was an area in which the findings from the women and clinicians were in agreement. Some clinicians appeared to attempt to espouse the values of *A Patient-Centred Approach* (a subtheme of *Trust*), which was at odds with the second theme identified, that of *The Clinician's Preference.* This theme represented the importance of clinician preference (either suggested or stated), which may have been linked to a specific 'reconstructive culture' at each site, driving trends towards particular procedures. The final theme developed was that of *Clinical Restrictions of Choice*, which were rarely mentioned by the women in this study. Findings between the women and clinicians were then compared, suggesting the possibility that using a particular type of language in the consultation may influence choice, even in the absence of overt expression of preference; this will be explored further in the next chapter.

CHAPTER 6 – DISCUSSION

6.1 Introduction

Breast cancer is the most common malignancy in the United Kingdom; there were approximately 54,500 new diagnoses in the United Kingdom in 2016 (Cancer Research UK, 2019). When treatment entails mastectomy, there are various reconstructive modalities that can be offered to women. This study explored the breast reconstruction decision-making experience from the perspectives of women, and the clinicians involved in their care. Findings from this study are presented in the context of national guidance developed by the Association of Breast Surgeons (ABS) and the British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS): *Oncoplastic Breast Reconstruction: Guidelines for Best Practice* (Rainsbury and Willett, 2012), which was the current guidance at the time of data collection and initial writing. The first quality criterion set out in the guidance states that oncoplastic breast surgery should be discussed with 100% of patients requiring mastectomy. This guidance also states that "*All relevant options should be discussed and with equal weighting, irrespective of whether they are available locally.*" (Rainsbury and Willett, 2012; p11) Findings of the National Mastectomy and Breast Reconstruction (NMBR) Audit, although now dated, suggested that equal weighting may not be given to all the relevant options in discussions with patients – this is supported by the findings of this study.

In Chapter 1, I established that a closer examination of how women choose a type of breast reconstruction was warranted based on key findings from the NMBR Audit (Jeevan et al, 2014). For example, implant-based reconstruction was the most frequently chosen immediate reconstruction and also chosen by one in four women undergoing delayed reconstruction (see sections 1.4.3 and 1.4.4 for explanation); however it yielded the poorest satisfaction on three of four scales. This was despite women reporting they generally felt that information provision was good (Jeevan et al, 2014). There was significant variation in the rate of offer and uptake of immediate reconstruction nationally, and significant variation in choice of free flap and pedicled flap reconstruction in one specific cancer network, that could not be accounted for by differences in the local population. These findings suggested that more information was required to better understand how women choose between the different types of breast reconstruction. In Chapter 2, I undertook a systematic review of the qualitative literature to answer the research question: *What do women with breast cancer perceive as influential when choosing a type of breast reconstruction?* I developed six themes that addressed this question: *Appearance, Return to Normal, Natural, Perception of Reconstruction Risks, The Surgical Consultation,* and *Body Ethics*. However, there are limitations to these findings, as the participants sampled in the studies that were reviewed were not necessarily representative of the wider population. As the studies that directly explored choice originated from the USA and the Netherlands, the decision-making of British women also remained largely uncharted. In order to better understand how these decisions were made, I designed a study that involved recruiting and interviewing twenty women and six clinicians, to explore what was important to women when choosing a type of breast reconstruction.

Two major themes that describe the influences that impacted women's choice of type of reconstruction were developed from my analysis of the interviews: *Caring for the Body* and *The Influence of the Surgeon*. The first theme introduced three approaches to caring for the body, that women in this study expressed. These were entitled *A Practical Decision, Perceptions of Risk* and *Preference for the Natural.* The first approach explored how some women chose implant-based breast reconstruction for pragmatic reasons as it enabled speedy re-integration into their normal life. The second approach, *Perceptions of Risk,* introduced how women's attitudes to risk influenced their choice of reconstructive modality. *Risk and the Assaulted Body* represented a subgroup of women, whose decision-making was founded on a more radical approach to risk reduction and preservation of what they saw as a healthy body, resulting in choice of an implant-based reconstruction. The final approach, *Preference for the Natural,* was the most frequently expressed in this study, and represented the primary rationale for choice of autologous reconstruction. *The Real and Reconstituted Body* subordinate theme represented a subgroup of women who valued natural reconstructions, for whom autologous reconstruction aligned with their values about reconstruction as an embodiment related to authenticity and 'goodness', in contrast to implant-based reconstruction. The major themes developed from the clinician interviews included *Trust, The Clinician's Preference,* and *Clinical Restrictions on Choice* and outlined the extent to which they shaped women's decision-making.

In this chapter I will draw upon the literature in order to provide insight into the decision-making of the women interviewed for this study, as they chose a type of breast reconstruction. Firstly, the concepts of 'normal' and 'natural' will be discussed, as two overlapping narratives that appeared to be motivating influences on many women's decision-making, followed by a discussion of moral rationalisations for choosing an autologous reconstruction. I will then discuss *Perceptions of Risk* in breast reconstruction decision-making, and provide a theoretically driven explanation of how risk perception modulates breast reconstruction decision-making. Next, I will explore contralateral prophylactic mastectomy and its connection to implant-based reconstruction in this study, as there was an unexpected number of women in this study who elected to undergo CPM. Following this, the influence of the woman's local community will be discussed, as three South Asian informants described similar experiences that affected their breast cancer journeys. An interesting aspect of this study was the inclusion of healthcare professionals involved in delivering the breast reconstruction services to the women who participated. The findings from clinician interviews will be discussed, including the influence clinicians may have had on women's decision-making and in particular the language used to describe the various procedures and possible complications during the surgical consultation. The contribution of this thesis to the existing literature will then be discussed, along with recommendations for future clinical practice, to better support women as they make a life altering decision, in a complex breast reconstruction landscape. Finally, the strengths and limitations of this study will be presented along with recommendations for further research, followed by concluding remarks.

6.2 Preference for the Natural

In Chapter 4, I presented the subtheme of *Preference for the Natural*. The desire for a natural reconstruction was a narrative that appeared frequently in women's accounts of decision-making. This was intimately linked with choice of an autologous reconstruction. In this section I will discuss how the *Preference for the Natural* was not in fact a completely conceptually clean construct in women’s accounts but overlapped with other concepts, namely the normal and practicality. I employed Denford et al’s framework which offers a categorisation of various interpretations of what constitutes normal (2011 – see section 4.4.2). This framework identifies ‘natural’ as a type of normality. This overlap between what is normal and natural surfaced in this study but also there were accounts where the two constructs were distinct. Also, most women who chose an autologous procedure would have had to balance their preference for the natural (with varying degree of emphasis) with circumstances that allow them to be suitable for such a reconstruction. Consequently, in this section I also argue that many women choose a type of breast reconstruction balancing personal preference and practicality.

In the breast reconstruction consultation, the meaning ascribed to a desire for a natural reconstruction appeared to be interpreted by clinicians as a preference for an autologous reconstruction, and this interpretation was seemingly readily agreed to by women. An objective view however could find the procedure unnatural, as it involves the relocation of abdominal adipose tissue or latissimus dorsi musculature onto the chest wall to form a breast shape. This creation of a flap was nonetheless perceived by these women as more natural than implant-based reconstruction, and for some more natural than not having a reconstruction. To some women, natural therefore implied reconstitution of a natural or normal-looking form, although arguably a more ‘natural’ solution would be to not have reconstruction. In effect, ‘natural’ was seemingly widely understood as a preference for a reconstituted embodiment, that included what a ‘normal’ breast should look like. It extended to women choosing a ‘natural’, autologous reconstruction as it will age with the rest of the body, allowing them to appear ‘normal’ as they grow older.

Although some of the women in this study who indicated a *Preference for the Natural* may have blurred the construct of ‘normal’ with that of ‘natural’ in their thinking, ‘*Looking natural’* (Denford et al, 2011) and *being* natural, were distinct to some women who participated in this study. For the subgroup of women that expressed a distinct preference driven by wanting to *be* natural, natural indicated an alignment with a set of values more akin to purity or being uncontaminated. Being natural evoked connections to a certain ‘goodness’, with attached moral imperatives as the natural treatment, or option, was seen as the *right* thing to do. Consequently, those who placed importance in *being* natural were more committed to the notion of autologous reconstruction than those who simply sought to look natural. Although this cannot be definitively determined by this study, I would posit that women who sought to *look* natural may choose autologous reconstruction if clinically feasible, but their choice might also be influenced by other factors, such as the surgeon, or personal circumstance. The value of *being* natural is seen in other decision-making processes, and can be likened to women perceiving a particular value in breastfeeding their children, as it is seen as a natural process (Ayton et al, 2019). Similarly, some patients prefer 'natural' solutions when possible, for example choosing complementary and alternative medicines (or treatments) (Astin, 1998, Bishop et al, 2005). This is thought to be due to what Astin (1998) termed a 'philosophical congruence with personal values', religious philosophy, or beliefs related to the nature of illness. It must be stressed that this type of decision-making was limited to a subgroup of women and it is unclear how widely transferable it is.

Based on the analysis of interviews with women in this study, I suggest that most women who chose autologous reconstruction did so balancing a *Preference for the Natural* and practicality. Preference for what was understood as a 'natural' procedure involved a complex surgical technique that must take into account individual feasibility. Some circumstances did not facilitate access to or offer of autologous reconstruction, or completely autologous reconstruction. For example, physical constraints such as lack of abdominal tissue, radiotherapy, and perception of limited range of available types of reconstruction locally, led to some women feeling they were 'steered' towards an implant-based reconstruction, or required an implant-assisted autologous procedure.

Woman often chose IBR for pragmatic reasons, such as the women represented by *A Practical Decision,* but even women who chose implant-based reconstruction based on risk, may have found it impractical to care for multiple wounds, for example on the abdomen, or the back. Consequently, I suggest that most women must balance their personal preference with individual feasibility when choosing a type of breast reconstruction. A recent qualitative study exploring how women choose a type of breast reconstruction (Giunta et al, 2021) published after data analysis was completed for this study, identified practical reasons that influenced how women choose a type of breast reconstruction, which they described as *Feasibility*. This formed part of the deliberation phase of decision-making, along with *Values and Preferences*, which they explained was a preference for options which align with values. The authors also identified *Social Influence and Support,* and *Pressure to Decide,* totalling four components that impacted on the deliberation phase of breast reconstruction decision-making. These four components have resonance with the findings from this study, (the latter, primarily by participants 0209 and 0210).

In summary, this section has served to introduce women's *Preference for the Natural*, which represented a core theme underlying the motivation of many women who choose to have breast reconstruction. Primarily, I have suggested that irrespective of women's personal preference for the natural, decision-making in breast reconstruction must be balanced with practical concerns. Further, I proposed an important distinction that may exist in the 'natural' discourses - between *looking* natural, and *being* natural. The former implies a personal preference for autologous reconstruction, whilst the latter signifies decision-making characterised by moral imperatives. I expand on this moral discourse in the next section.

6.3 The Real and Reconstituted Body

In Chapter 4, I introduced *The Real and Reconstituted Body*, a subordinate theme of the *Preference for the Natural* approach to caring for the body. It represented the decision-making experience of a subgroup (n=4) of the ten women who chose autologous breast reconstruction. This group of women believed that breast implants were closer to vanity improvements than reconstruction , and saw an inherent value in using one's own tissue in reconstruction. The decision-making narrative for these four women was imbued with moral imperatives, which in this context suggested there were right, or wrong decisions. I offer two interpretations that may provide insight into the moral rationale behind choosing autologous reconstruction. Firstly, there is the notion of a moral type of femininity, in which socially sanctioned interpretations of femininity are viewed as *good* or *right* (Saxena, 2013). Secondly there is the idea of hard work and persistence, despite the challenge presented by the breast cancer experience, reaping rewards in the future. The latter notion is reminiscent of the Protestant work ethic, also known as the Puritan or Calvinist work ethic, a term first introduced in Max Weber's *The Protestant*

Ethic and the Spirit of Capitalism (1905). Weber explores this work ethic, in which hard work is associated with salvation and the pursuit of a righteous life, promoting God's glory; this is reminiscent of some women's suggestions of labour and reward in complex procedures (see section 4.5.2.1).

It is not surprising that a moral discourse appears in the context of breast reconstruction, given the frequency with which it appears in relation to women's health (Nack 2002, Lupton 2012, Purcell et al 2014, Sheehan et al 2019). The female body is a contested space, with judgement expected or experienced in various aspects of health, including reproduction, abortion, motherhood, menopause/hormone replacement therapy, sexuality and in this case, breasts (Nack 2002, Lupin et al 2012, Purcell et al 2014, Sheehan et al 2019). The intricate societal understandings of what constitutes a 'good' woman that seem to exist within women's health, and in particular care of the breasts, were apparent in this study of breast reconstruction, just as they have appeared in the breastfeeding literature (Ayton et al, 2019, Sheehan et al, 2019, Thompson et al, 2020). For example, it is argued by some feminist scholars that having breast reconstruction implies conformity to unnecessary social norms; that one-breasted women are made to feel 'physically handicapped' in patriarchal society (Crompvoets, 2006). Yet younger women have reported facing some difficulty when deciding to decline reconstruction after mastectomy, even by their surgeons (Holland et al, 2014). Some women in this study expressed opinions that major surgery (in the form of reconstruction) may enable them to attract a future partner, which speaks to perceived societal beauty standards. On the other hand, women in this study indicated they anticipated being labelled vain, for choosing to have reconstruction. In particular, choosing to have implant-based reconstruction was linked to women who might be described as sex symbols or sexualised celebrities by some women in this study. Evidently, there are complex perceptions of societal expectations embedded in choices to have, or decline, breast reconstruction, and type of breast reconstruction chosen.

In order to demonstrate why I suggest that some of the women who participated in this study are engaged in a moral narrative, I will expand on the role of morality in decision-making. Lee and Ungar defined moral categories as follows:

> *"When, at a given time in a social system, there are strong expectations for individuals to place themselves in an essentially dichotomous classificatory scheme, in relation to some highly sanctioned rule of conduct, and these self-placements are widely used and salient for labelling themselves and others, then we speak of a moral category"* (Lee and Ungar, 1989, p 692-3)

This definition provides some explanation of the binary labels the women in this study used in relation to reconstruction – real or false, natural or foreign, good or otherwise. Lee and Ungar (1989) identified five forms of moral rhetoric, based on: *logic, rights, feeling, affinity* and *fairness and goodness*.

Although published over 30 years ago, and predating the time of routine breast reconstruction, nonetheless Lee and Ungar's descriptions of what constitutes a moral argument can be applied to understand the discourses used to discuss breast implants adopted by some women in this study . These breast implant narratives can be explained by two different forms of moral rhetoric - *feeling* and *affinity (*Lee and Ungar, 1989). Moral rhetoric grounded in *feeling* was first identified by 17th century philosophers, Adam Smith and David Hume, who suggested that action is driven by sympathy and empathy; by passion as opposed to reason: "*Reason shows us means, but sentiment selects ends"* (Hume, 1960, p135). These discourses suggest consequences that engender pride, or shame; actions that make the individual feel better for having chosen, or worse if left undone (Mackie, 1977). It is suggested that the decision is at its core an emotional response, and then a moral reasoning follows. Applying this to breast reconstruction and the women in this study, the moral argument used against breast implants may be expressed in part by an initial, almost visceral, reaction to the suggestion of something foreign introduced into the body, and therefore repugnant (see also e.g.. Martin, 1990). These women held such strong views towards foreign bodies that they immediately discounted breast implants. This immediate reaction may then be followed by a rationalisation that implants are unnatural, and will not age naturally with the body, reinforcing them as 'other' and immoral.

The accounts that led to the development of *The Real and Reconstituted Body* subtheme also contained rationalisations that align with the notion of *affinity*, a desire to adopt an ideal that provides good standing in a group (Lee and Ungar 1989). For these women, I suggest they may have wanted to be perceived as *good* women in society, through their choice of reconstructive option. This perhaps links to a value system that subscribes to a perception of a 'good' femininity, rooted in negative views of breast implants, based on their connection to cosmetic surgery, which has been linked to vanity, narcissism and psychological issues in the media (Saxena, 2013). Saxena (2013) explored the experience of women who had breast implants and the way their experiences were shaped by the stigma attached to this procedure. After having cosmetic breast implant surgery, these women felt that they had moved from feeling 'abnormal' (for having perceived small or inadequate breasts) to feeling 'unnatural', and faced with living with an 'inauthentic' self; that is, they had traded a physical stigma for a one related to their moral character (Gimlin 2000, Saxena, 2013). This stigma was described by Saxena (2013) as based on cosmetic breast enhancement surgery with implants being linked to women with 'loose' sexual behaviour. Breast implants therefore implied a 'bad' label associated with women's moral character, as opposed to 'good girls' who adopt a socially approved version of femininity (Saxena, 2013). So breast implants and the women who had them (whatever the reason), could be perceived as engaging in vanity improvement – 'bad femininity'. Consequently, I suggest that affinity towards a socio-normative 'good femininity' may also explain the moral argument towards choosing autologous reconstruction for these four women.

This disapproval of breast implants and consequently implant-based reconstruction, may offer some insight into why some women in this study indicated that they would have declined any reconstruction if they could not have an autologous reconstruction. But for those represented by this subtheme, there was also a certain goodness reflected in their decision to choose an autologous reconstruction, indeed some women spoke to the importance of their new breast being a "part of [them]" (0108). This was rooted in a notion that it was natural, and of the body. I argue that for some women, the value placed in tissue-based reconstruction carried more weight than just avoidance of a misdemeanour for choosing a breast implant – it appeared to be viewed as the 'right' option. It was not simply a logical rationalisation as the opposite of a breast implant. The descriptions of the struggle, or arduous nature of the reconstructive journey, which some women even seemed to value (0106), had resonance with the Puritan work ethic. The breast cancer experience and reconstruction therefore linked to hard labour, and rewards such as those of the abdominoplasty of the DIEP, or even just a 'natural' breast, suggest a moral argument for choosing an autologous reconstruction for some of these women, more than simple avoidance of an implant.

It was previously thought that women who choose an implant-based reconstruction after mastectomy would not be judged negatively as they have a ‘virtuous’ or heroic reason (in breast cancer) for requiring breast implants (Saxena, 2013). A contribution that this study makes to the breast reconstruction literature is that this virtue rationalisation may no longer hold for everyone. The participants in this study whose accounts form *The Real and Reconstituted Body* subtheme adopted a discourse of morality, and justified their choice of reconstruction type on the basis of their pejorative views of breast implants.

This shift in social acceptability of breast implants, could be part of a change in breast cancer narratives over time. One of the first major works examining breast cancer narratives was Susan Sontag’s ground-breaking *Illness as Metaphor* (1979), which brought awareness to a disease that previously went unmentioned in society, in part due to taboos surrounding cancer. Her work explored the use of metaphor in cancer, including the pervasive military and battlefield metaphors that dominate much of medical and patient discourse. She describes invasion of tumours, radiotherapy as aerial warfare (bombardment of patients with toxic rays), and chemotherapy as chemical warfare. The damage caused by these treatments were justified if a life is saved. The metaphor extended beyond the body as a battlefield, to society itself battling the enemy of cancer (Sontag, 1979). Battlefield representations of the fight against cancer also evoked portrayals of the patient as a hero in a struggle or battle, and linked to a discourse of hope and bravery in modern western society (Lupton, 2012). These descriptions of bravery were reminiscent of the views of some of the women in this study who chose autologous reconstruction. The struggle and labour of autologous reconstruction appeared to engender feelings of courage and even heroism in some of these women. These stories of heroism may have emerged from the ingrained battlefield metaphorical language these women may be exposed to, and provided a guiding narrative for some in their choice of autologous reconstruction.

By the early 2000s, a new narrative entered the breast cancer landscape. Barbara Ehrenreich's oft-cited article *Welcome to Cancerland* (2001) described different cultural narratives around cancer. Breast cancer had changed, from an unmentionable disease to a well-publicised one, with extensive corporate support. Major companies advertised their support of fighting the disease, and the public would fundraise to raise awareness and support research. The pink ribbon symbolising breast cancer was worn on clothing, worn as jewellery, and sold as homeware (candles, mugs, etc). The battlefield and survivorship narrative became commercialised, focussed on raising awareness and fundraising. The typical survivor was a middle class, white woman, with a feminine persona and always cheerful (Ehrenreich, 2001). Notably, Ehrenreich described the beginnings of a new breast cancer metaphor, that of the makeover, which seemed increasingly relevant:

> *"And in our implacably optimistic breast-cancer culture, the disease offers more than the intangible benefits of spiritual upward mobility. You can defy the inevitable disfigurements and come out, on the survivor side, actually prettier, sexier, more femme"* (Ehrenreich, 2001; p49)

The makeover metaphor has been described as: "…*a widespread cultural discourse that is exemplified through elective cosmetic surgery and the apparent ability of the neoliberal subject to choose, guide, and take sole responsibility for the process of refashioning the body, despite the necessity of submitting to technological expertise*." (Cobb and Star, 2012; p98). It has been described as a form of post-feminism, as it adopts the language of the traditional western feminist and transforms it into individualist and consumer discourses (McRobbie 2009).

This shift from military to a makeover metaphor in breast cancer narratives may distract from the medical breast cancer experience, of diagnosis, treatment, pain and complications, and instead constructs the experience as one of positive personal transformation, by refashioning the body through reconstruction (Cobb and Starr, 2012). I argue that a view that guided the breast reconstruction decision-making experience, based on the accounts of the women who are represented by *The Real and Reconstituted Body*, may have been in part influenced by the makeover metaphor. However, these women did not discard the battlefield narrative, as that heroism may have led some to choose autologous reconstruction. Rather, they seemed to incorporate the language of positive personal transformation, placing less emphasis on cancer as a battlefield; this was possibly influenced by the normalisation of breast cancer discourse in society (Ehrenreich, 2001).

6.4 Risk

Individual women's approach to risk, both that associated with a procedure, and of breast cancer itself (ie contralateral breast cancer), was a major factor in decision-making in this study. As described in Chapter 4, those who expressed greater concern about risk did not choose autologous reconstruction and often also opted for a contralateral prophylactic mastectomy. Women who chose autologous reconstruction were typically less concerned with operative risk, opting for the procedure that matched their aesthetic and personal preference. The approach to risk was guided by two major factors, firstly individual perception of risk, and secondly, by how it was communicated. As presented in Chapter 4, women were aware of complications that were common or concerned them but did not explicitly describe how risk was communicated with them, for example with figures or comparative risks of procedures. Similarly, in Chapter 5, I explained how clinicians did not specifically mention how they communicated risk as part of their consultation (apart from brief suggestion of provision of leaflets and figures), nor did they disclose any concerns about how women perceived or acted upon risk. However, fear of certain risks did directly influence women's decision-making, for example some described fears about autologous reconstruction, due to a possibly inflated concern of associated flap failure. Overall risk in the interview data was often implied qualitatively or linked to a particular type of procedure. This section shall explore and contextualise risk perception and communication in breast reconstruction.

Risk Perception

An important aspect of both risk communication and perception, introduced in Chapter 4 (see section 4.5.1.2), is the interpretation of risk, if presented as a number. Although women did not recollect specific figures, one reason for different perceptions of risk may relate to the manner in which numerical figures were interpreted by women. Historically, clinician assessment of risk was primarily qualitative, based on professional authority, experience and individual judgement. The introduction of multivariate indices for approximating discrete surgical risk was rapidly adopted by clinicians, after the first adverse surgical outcome index was published in 1977 (Neuman and Bosk, 2012). Surgeons often communicate information about likelihood of complications to patients as discrete values, which may test their numerical literacy. Peters (2012) describes how numeracy affects judgement and decision-making. It is related to, but separate, from general intelligence, and those who are highly numerate and innumerate respond differently to quantified risk communication. Those who are less numerate may struggle with converting numbers between different formats such as equivalent percentages and frequencies. In fact, the less numerate may even perceive a greater risk with equivalent values presented as a frequency as opposed to a percentage. The less numerate may also be more sensitive to narrative and emotional information that competes with numerical information, with decision-making affected by different mood states (ie framing effect). The importance of numeracy in breast cancer decision-making has been studied, suggesting that women who were more numerate were able to better identify treatments associated with cancer-free survival than those who were less numerate (Lipkus et al 2010).

Likely more important than the interpretation of a numerical risk to the women in this study was cognitive bias, a systematic error in judgement occurring in individuals as they process or interpret information. An example may include women who chose implant-based reconstruction because they thought that autologous procedures were high risk for flap failure, when in actuality, it occurs in 2-3% of DIEPs (Gilmour et al, 2021). This can be explained by a type of cognitive bias called the availability heuristic - when an individual judges an event as frequent or likely based on ease of imagination or recall, as opposed to its actual frequency. It has varying effects on risk perception, one of which includes low-probability risks being interpreted as more common due to simple discussion or introduction, despite evidence of improbability. Cognitive bias in risk perception can significantly augment decision-making; Slovic et al's (1980) seminal work describes these biases in depth. The media plays a large role with this type of judgmental bias as well, given that it affects what individuals recall about events. The availability heuristic can explain why women view certain complications as common, in particular implant loss, given the wide media coverage of breast implants (see Chapter 4).

Once a belief is formed, the authors (Slovic et al, 1980) stated that individuals' beliefs are often persistent despite presentation of contradictory evidence (termed *Reconciling Divergent Opinions about Risk)*. So ingrained beliefs, for example, that breast implants fail and rupture, or are foreign bodies that cause inflammatory conditions, may persist after the aforementioned media scares (see Chapter 4) and discourage choice of implant-based reconstruction in the future. This may add to the understanding of why younger women choose IBR more often (Manrique et al, 2019), as they were less likely to have been as affected by the media in the 1990s and 2000s, when numerous incidents with breast implants were reported .

Slovic and Peters (2006) propose two approaches to perception of, and acting upon a risk, which they describe as *Risk as feelings* and *Risk as analysis.* Risk as feelings describes an instinctive and intuitive reaction to danger. Risk as analysis involves deliberation, and use of logic, in risk assessment and decision-making. The breast cancer and reconstruction experience according to the women interviewed in this study is typically laden with emotion, engendered by existential concerns, as illustrated in the accounts of women described in the *Risk and the Assaulted Body* group. Consequently, the influence of emotion must be considered when discussing the effect of the breast cancer experience itself on risk perception. Both types of risk perception are important - 'risk as feelings' was thought to have developed to enable humans to survive/evolve, guiding, for example, whether an animal was safe to approach. They label it as an intuitive, natural and automatic way of interpreting reality. Two major emotions augment perception of risk, fear and anger. Fear amplifies risk estimates whilst anger reduces them; calmer states are guided by subtler emotions. They have termed reliance on such feelings for risk perception as the 'affect heuristic'.

The importance of the affect heuristic (Slovic and Peters, 2006) is that individuals often perceive risk based on the strength of the positive or negative emotional response towards the activity/event. Consequently, risk is inferred to be low, and benefit high, for something for which one has a positive feeling. Conversely, risk is inferred to be high, and benefit low, for something that evokes a negative feeling. So in breast reconstruction decision-making, if a type of reconstruction evokes a certain feeling, the approach to risk will follow suit. This is perhaps the most important cognitive bias that could modulate choice of type of breast reconstruction. If an implant evokes an ‘unnatural’ feeling, risk of implant rupture may feature highly in the decision to choose an autologous procedure. This represents an interesting similarity to the moral category of *feelings.* In both moral and risk-based rationalisations of decisions, choices can be strongly based on feelings. Extending this notion, if the breast cancer experience itself evokes a sense of fear, all aspects of the reconstructive decision may be perceived as high risk. This may offer an explanation of the decision-making of the women of the *Risk and the Assaulted Body* discourse. Due to fear of recurrence of breast cancer, they acted on a possibly amplified concern of risk of contralateral breast cancer by choosing contralateral prophylactic mastectomy. It is interesting to note that the influence of the affect heuristic extends to patient numeracy as well (Slovic and Peters, 2006). When consequences carry a strong emotional cue, which can include winning the lottery as well as cancer, their probabilities carry little weight (some termed probability neglect).

The suggestion that both moral and risk-based rationalisations in decision-making may in fact follow, as opposed to precipitate, a salient emotion towards a reconstruction, or away from a particular reconstructive risk, is important in the understanding of how women choose a type of breast reconstruction. Some women will choose a reconstruction first, and rationalise after. This is in some ways reminiscent of an older breast reconstruction decision-making model, introduced by Diana Harcourt in 2004. This model explored how women chose to have reconstruction or mastectomy only. Three types of decision-makers were identified, the relevant one being *Instant/immediate decision-makers*, who accounted for the large majority of women, and generally made decisions effortlessly (Harcourt and Rumsey, 2004). Of the subthemes identified within the *Instant/immediate decision-makers*, one was entitled *Salience*, which holds particular relevance to some of the women who participated in this study. It describes decision-making that is based on an immediate response to an aspect of reconstruction that was salient to the individual, and subsequently built upon as a template for the reconstructive decision. It is readily applicable to many of the women in this study who found salience with various notions, including *natural, risk-reduction,* and *implant complications*, to name a few. So when women find an immediate connection with for example, the natural (which is usually accompanied by the view of implants as unnatural), the emotions generated may result in reduced perception of risk for procedural complications, and amplified perception of risk of implant rupture, which is then used to rationalise the decision.

Risk Communication

The influence of the surgeon is clear from the reports of women participating in this study. As the primary and most trusted source of information to many women, the manner and content of risk communication by surgeons carried significant weight. As described in Chapter 4 (see section 4.5.1.2) and 5 (see section 5.4), the communication of risk at the recruitment sites was likely atypical, and may have been inadequate for women to be truly informed. To reiterate, it was noted that some women seeking to avoid reconstructive failure chose IBR in this study, viewing autologous reconstruction as high risk for flap failure. However, current guidance suggests only a 2-3% chance of flap failure for DIEPs (Gilmour et al, 2021), whilst the iBRA study (a large, UK multicentre, prospective cohort trial of immediate implant-based reconstruction with and without mesh) found a 9% rate of implant loss at 3 months (Potter et al 2019). Clearly, the risk of reconstructive failure is higher for women having implant-based reconstruction, which raises certain questions about how risk was communicated in their pre-surgery consultation. This section explores factors that influence how risk is communicated.

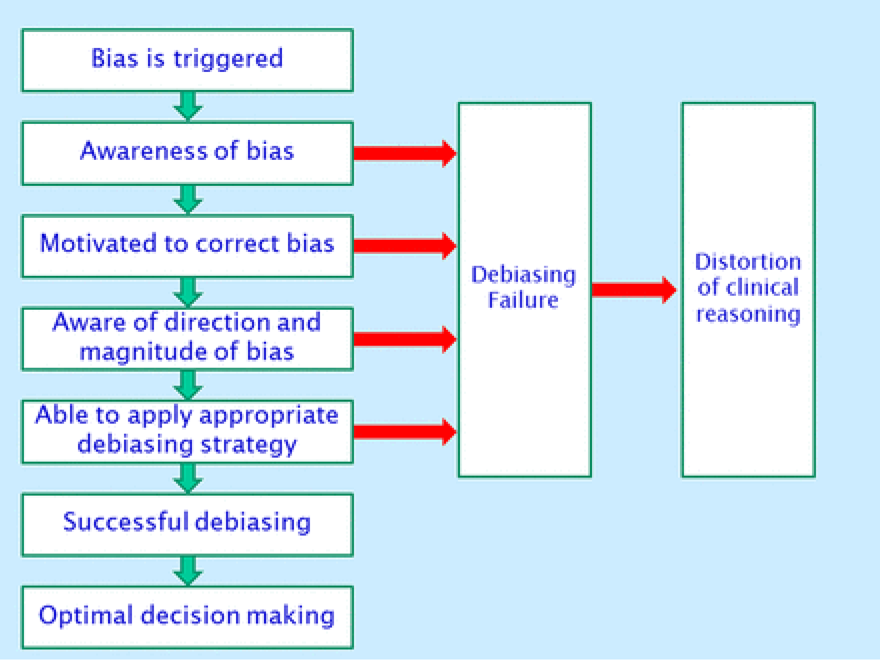
It is unlikely that clinicians knowingly disseminate inaccurate or outdated figures relating to overall or specific clinical risks. However, even with the provision of accurate figures, the ability to interpret numbers and basic statistics is a core difference in the approach to risk, between surgeons and women. Although a dated study, it was estimated that over 75% of the adult UK population had numeracy skills that were less than a ‘good pass’ at GCSE level (Houses of Parliament, 2008). So even if accurate numerical risks are provided to women in order to compare between reconstructions, many women will not be able to understand decision-making based on numerical risk, to the level that may be expected by the surgeon. It may be that women who felt ‘steered’ may have been directed to a choice due to a surgeon’s risk-based reasoning that they didn’t understand, or required radiotherapy. Nonetheless, presentation of individual risk is vital in order for patients to make an accurate risk/benefit assessment, and is therefore a necessary component of surgical shared decision-making (Pellise et al, 2022). The onus is therefore on the clinician to present risk in a format that women, including less numerate ones, can understand. Solutions include: provision of numbers in equivalent percentage format, and avoiding change between frequencies and percentages (Peters et al, 2011); labelling the evaluation of numerical risk, for example as 'poor' or 'excellent'; and supplementing numerical information with visual ones, for example pictographs (Peters, 2012). Notably, women in this study described risk with words as opposed to numbers, so it is possible that some clinicians may have catered to the less numerate, but they rarely described comparative risk assessments, without which these descriptions are less useful.

More than simply offering a procedure based upon likelihood of specific risks or overall risk, risk assessment (and therefore communication) may have been modulated by other factors mentioned by clinicians, such as women's preferences, women's personal factors, their own personal experience, and surgical consumables (ie ADM); surgeons' intuition plays a role too (Pellise et al, 2022). However, the assessment of risk itself by surgeons can be quite variable (Sacks et al, 2016) and has even been described as 'heterogeneous and discordant' (Pellise et al 2022).

There is also the possibility that clinicians are affected by cognitive bias, impacting how they make decisions, and assess and communicate risk (Croskerry et al, 2013, Elston 2020, Pellise et al, 2022). Certain situations, such as sleep deprivation, fatigue and cognitive overload can increase cognitive bias in clinicians (Croskerry et al, 2013). Biased reasoning may also be precipitated by the development of an emotional response to a particular patient. These responses can lead to different types of biases including: confirmation bias (a bias towards one's existing belief), anchoring bias (a bias based on just the initial data, or fixating on the initial assessment), and availability bias (bias towards the diagnosis that most easily comes to mind) (Croskerry et al, 2013). Furthermore, if patients are subject to the affect heuristic, then it is possible that some surgeons will also assess risk in favour of their preferred procedure. In this study, confirmation bias, the tendency to confirm with own beliefs or in this case surgical preference, may have also contributed to the ways risk, or information about the various choices, were presented. Cognitive biases are often unconscious, and as such risk assessment and communication may be unwittingly tailored.

The way surgeons assess and communicate risk as well as cognitive bias may have contributed to the geographic variation in the uptake of breast reconstruction and the uptake of particular types of reconstruction (see Chapter 1). Croskerry et al (2013) discuss cognitive 'debiasing', as a strategy for avoiding systematic bias in clinical decision-making. They suggest various models guiding how to limit bias (see Figure 6.1 below); these often begin from a place of awareness and reflection, placing emphasis on the thoughtful, reflective surgeon.

Figure 6.1 – Successive steps in cognitive debiasing – adapted from Wilson and Brekke (1994) (reproduced from Croskerry et al [2013] with permission from BMJ Publishing Group Ltd)



Expanding upon the importance of the thoughtful, reflective and aware surgeon, this study's findings suggest that *how* clinicians utilise risk during their consultations requires attention too. Women did not specifically disclose how comparative risks were communicated to them, although specific complications were described when they excluded an option for women. Earlier in this section I proposed that women's risk-based rationalisations for their breast reconstruction decision may be built upon a preference for, or emotional response to, a salient reconstructive feature, that they may link with a particular belief. So risk may perhaps be used as a tool by women, to rationalise their decision. In the reconstructive consultation, risk may have been used similarly by clinicians as a negotiation tool, to influence women's decision-making towards a particular reconstruction. Recall C104, who advised women who preferred implant-based reconstruction of the 'crippling months or years of complications' associated with this procedure. Although clinicians may suggest that risks were presented fairly, when used as a negotiation tool, risk may be communicated and presented in such a way that is shaped towards the clinician's preference. This would represent a communication bias, at odds with patient-centred care.

6.5 Contralateral Prophylactic Mastectomy

There was an unanticipated number of women who chose contralateral prophylactic mastectomy (CPM) in this study (see section 4.5.1.2), in the absence of any known predisposition to contralateral breast cancer. For many of these women, the narratives that underscored the decision to have CPM also drove the choice of IBR. The participants themselves did not describe the link between these choices. Although this data was not collected, CPM may have been a more frequent occurrence at Site 2; this may indicate differences in how CPM was presented by local surgeons, although no mention of this was made by the women or clinicians, and this was not asked specifically in the interview schedule. This section aims to explore CPM and what drives it.

Despite the fears expressed by women opting for CPM, they are not thought to be well founded from a scientific standpoint, and national bodies representing breast surgeons in the US and the UK recommend that most women do not require CPM (Boughey et al 2016, Bramley et al 2017, Carbine E et al 2018). Yet CPM rates are rising in the UK and the US (Ashfaq et al 2014, Agarwal et al 2015, Chen et al 2019, Neuburger et al 2013). The qualitative literature outlines many reasons why women choose CPM, including fear of contralateral breast cancer, and hoping for peace of mind with CPM (Ager et al, 2016). Related influential factors include vulnerability and survival. Women have reported such a pervasive sense of vulnerability that any risk (even when low), was intolerable (Ager et al, 2016). Some propose that women who chose CPM often *mis*understand risk (Greener et al, 2018); others suggest it is done not due to risk perception, but for psychological reasons (Beesley et al 2013). Other common narratives regarding CPM include an underlying motivation of 'taking control of cancer' (Covelli et al 2014), and reclaiming the body and moving forward (Tollow et al 2019). Often, those choosing CPM feel that they have put their life on hold, necessitating CPM to move on (Beesley et al 2013), again suggesting that CPM has primarily a psychological benefit for some women.

The evidence suggests that patients typically introduce the CPM conversation, but often find it quite challenging to be allowed to have CPM by their surgeon, likening it to a battle (Beeseley et al 2013, Tollow et al, 2019). However, there are also varying accounts of clinician influence of the choice to have CPM, with Ager er al's review (2016) suggesting instances of physician encouragement, and Greener et al's 2018 study suggested a 'subtle push' towards CPM (note is made that the studied populations were in the United States). No difficulties with or encouragement of CPM were noted by women at Site 2.

Identifying contributing factors to choosing CPM is important, as it represents a definitive, invasive procedure that is not required from an oncological standpoint (apart from specific circumstances, for example hereditary breast cancers). In keeping with the importance of language that was introduced in Chapter 5 (see section 5.4), I suggest that the language of war, suggestive of the pervasive military metaphor, links these different risk narratives: the battle to have CPM, constantly being alive to the threat of cancer, the concerns of vulnerability and survival. Frequent exposure to the military metaphor could perhaps lead to heightened fears and preference for CPM. As explored in the previous section, induction of fear can be linked with amplified estimates of risk, which would be in keeping with a desire for CPM despite advice that contralateral breast cancer is statistically unlikely for most women. As offer of reconstruction is associated with uptake of CPM, this discourse is important to reconstructive surgeons as well. The breast reconstruction consultation can be an emotionally charged situation, and consequently clinical information may be misinterpreted by women.

6.6 Breast Reconstruction and a Woman's Community

The similarities in the experiences of the South Asian women I interviewed represented another important finding of this study (see section 4.4.3.2.2). In Chapter 4, I introduced their common narratives of isolation in the breast cancer experience, which have been reported in other immigrant South Asian communities in the literature (Grewal et al 2005, Gurm et al 2008, Patel-Kerai et al 2017). These women had negative views of the local South Asian community, who they felt discouraged reconstruction, on the basis of avoiding further suffering. They therefore isolated themselves, and shared their breast cancer diagnosis with just their immediate family and perhaps a few in their extended family. They were typically even more guarded with disclosure of their reconstructive procedure, partly due to fear of discouragement, and also for fear of engendering voyeurism of the sexualised (as opposed to rehabilitated) breast. Despite their perceptions of the views of the community, these women were proud of their bravery, for transcending cultural norms. In this section I shall explore some of the literature concerning South Asian women and breast cancer, and propose a common underlying narrative in breast reconstruction decision-making.

In some South Asian communities, emphasis is placed on women to uphold family honour and reputation; so disclosure of a stigmatising illness could bring shame on a family (Bottorff et al, 1998, Bedi and Devins, 2016). This shame may be associated with a belief that cancer is a form of punishment from God, and therefore women with breast cancer may be seen to have behaved in such a manner to warrant cancer (Gurm et al 2008, Patel-Kerai et al 2017). Other perceptions of the causes of cancer in South Asians can also include familial inheritance:

> *"The tendency for South Asian women to hide or not talk about cancer perpetuated this belief [that South Asian women didn't get breast cancer]. For many women there was shame associated with having cancer in the family. 'Like suppose I have cancer. The other people will say, "Oh no. Poor things. The children are going to be cancer cases… Today the mother has cancer. Tomorrow the children will have it."* (Johnson et al, 1999; p251)

Some have recognised a reluctance to speak about cancer in some South Asian women, as a form of self-preservation and protection of the family's honour (Johnson et al, 1999). This stigma towards the perceived 'weakness' of the family lineage of cancer patients has been reported in married South Asian women of varying faiths, including Sikhs, Muslims, Hindus and Christians (Bedi and Devins, 2016). There are also reports of ingrained behaviours of women in young ages, in which women are taught to be modest, keep family matters private, and put others in the family first (Botterff et al, 1999, Grewal et al, 2005). I suggest that these women's views may represent a 'good woman' narrative. The non-disclosure of breast reconstruction, descriptions of the importance of upholding family honour in the community, and concerns about public knowledge of the sexualised (reconstructed) breast, suggest that these women were performing the duties of a good woman in their culture.

These three women were the only participants to discuss their religion in this study. Indeed, "religion pervades the cultural fabric of [South Asian] societies." (Bedi and Devins, 2016; p44). All three women however described their respective faith as important, but this did not explicitly influence their decision-making – rather it helped to support them as they lived with their decisions. Similarly, a recent study exploring decision-making in breast cancer (as opposed to breast reconstruction) of UK ethnic minorities, found that religion played a supportive role, rather than an explicit influential role, in the decision-making process (Patel-Kerai et al, 2017). In Rubin et al's 2013 study of African-American women however, the concept of 'acceptability to God' was reported as influential in choices to decline reconstruction (this is what God desired), or opt for an autologous reconstruction (using what God has given) (Rubin et al, 2013). Despite there being no stated association between culture or religious belief and choice of type of reconstruction in this study, three of the four ethnic minority women chose an autologous flap. A large cohort study showed increased uptake of autologous reconstruction in both Asian and African patients in the UK, when compared to white women (Mennie et al 2017) – groups which may frequently be religious or spiritual. For those who decide to have reconstruction, I suspect that a 'natural' (autologous) reconstruction may be preferable to those who are more religious, or are integrated into a heavily religious culture, due to the association with moral goodness, as described earlier in this chapter. More research into the influence of culture on decision-making in breast reconstruction is recommended, as the findings in this study are based on interviews with only three women.

6.7 The Clinicians' Interviews

Three themes were developed from the interviews with the clinicians: *Trust, The Clinician's Preference,* and *Clinical Restrictions on Choice.* There was a marked difference between the themes developed from the clinicians and the women I studied. The primary area of agreement was the great influence of the surgeon on choice of procedure. Care must be taken when interpreting clinicians' accounts as they were derived from a small convenience sample drawn from two sites which may have been atypical given the possibility that a site-specific culture (see section 5.3.2) may exist. In the interviews there were examples where surgeons expressed preference (see C104) and also indirectly, for example through the volunteer available at one site as discussed in the findings. These data suggest that clinician preferences may play a role in driving local trends, establishing 'custom and practice' and this may contribute to variations in care, such as restricted access to free flaps.

The findings from this study indicate that surgeons must take care in expressing their preference, as women, and their self-identity may be vulnerable at this time. Extreme experiences, such as the existential threat evident in cancer diagnosis and experience, can challenge self-identity, which has been termed a biographical disruption (Little et al 2002, Lupton 2012). Reconstruction can provide a way to 'rebuild normal' and 'adapt to their new self' (Denford et al 2011). When women hold positive views of their surgeon, have a surgeon of good reputation, or extensive experience, then acceptability of breast reconstruction is increased, reinforcing the great role of the surgeon in breast reconstruction (Begum et al, 2011, Retrouvey et al, 2019). So should a surgeon disclose a preference, whether directly or indirectly, women may be more easily swayed, particularly as trust in surgeons is evident, and identity is challenged (or in flux) during this experience.

Again, this study involved a small convenience sample of clinicians, and it cannot be stated how widely this may occur in clinical practice. Two of the four surgeons interviewed made no mention of guiding their patients towards specific reconstructions and said they were explicit in the provision of balanced views, offering women all available choices. However, such guidance of women towards specific procedures by clinicians has been described in the literature (see section 2.4.2.5).

Although the literature and findings from this study suggest that preference in surgeons for a particular procedure does exist, this does not necessarily entail that all women will follow the surgeon's preference. One of the clinicians in this study stated that the influence of the surgeon was more pronounced in women who are not well informed, or those who had no personal knowledge of breast reconstruction. This was noted by a woman interviewed for this study as well, who stated that she accepted implant-based reconstruction, as she had no exposure to breast reconstruction, and trusted her surgeon's opinion. I offer a line of reasoning, which may explain why some women resist the preference of persuasive surgeons. I suggest that those with experiential knowledge of breast cancer and reconstruction, for example from the experience of family members, will construct perceptions as to how cancer would affect them (d'Agincourt-Canning, 2005). The established constructions of how cancer might affect them may reduce the risk of identity shift, or crisis, should they develop breast cancer. They may have had the time to contemplate which identity they would adopt and are therefore at reduced risk of influence from the surgeon. Like those who are informed or have had exposure, it may then be that those who have delayed reconstruction also have had time to develop their identity and therefore may also be less easily suggestable.

In Chapter 1, I introduced the tenets of patient-centred care. The clinicians I interviewed made reference to utilising patient-centred techniques which could help build trust in the surgeon, an influential factor in women's decision-making in breast reconstruction. Surgeons however also either expressed a personal preference of reconstruction, or were aware of other surgeons doing so; this was not unique to this site (Potter et al, 2013). Although clinicians have expressed preference in this study in the best interest of their patients, nonetheless this is at odds with a patient-centred approach. A truly patient-centred consultation involves sharing power and responsibility, and guiding patients towards a preference does not suggest an equal role in decision-making. Personal preference may also affect how surgeons communicate associated risks (recall C104's weighted description of implant complications); true shared decision-making should encompass accurate discussion of risks/benefits, and allow patients to explain their own values and preferences.

In this section I have explored the themes that were developed from interviews with clinicians, which represented what they thought was most influential to women when choosing a type of breast reconstruction. I have explained how trust in the surgeon and preference of the surgeon can greatly influence women, at a time when their identity is challenged. I have also identified how this encroaches upon patient-centred care.

6.8 The Language of the Surgical Consultation

As people become patients, they must learn a new, medical language (Appleton and Flynn 2014). Recall that in Chapter 4, the language used by the breast care nurses, calling a reconstruction a ‘midway’ procedure, seemed to have been adopted by one of the women from that site. The new terminology that women must learn when they become a patient with breast with cancer is extensive. Part of conveying this difficult new language involves providing tangible descriptions that are easily understood by women. Speaking in metaphors can aid discussion with patients, and are frequently used in healthcare - in particular, cancer care (Hendricks et al, 2019). In fact, speaking in metaphor pervades all avenues of verbal communication, as it is used as an ‘epistemological device’ that helps us understand the world and define notions of reality (Lupton, 2012; p57). Metaphors can help patients give meaning to illness, which can influence coping abilities as well as recovery (Lipowski, 1970). Furthermore, they can assist patients in conceptualising and articulating their experience to others (Lupton, 2012). These metaphors can include body as battlefield (military metaphor), body as machine, body as nation and even (more recently with technological advances), body as a computerised system (Lupton, 2012). Perhaps the most commonly discussed metaphor in cancer care is that of the military metaphor. In fact, ‘Cancer is war’ was the most commonly occurring conceptual metaphor in a study of cancer-related articles from *The Guardian* newspaper (Williams Camus, 2009). This type of metaphor was used in online writing by those with cancer, carers and healthcare professionals, as well as in interviews with these same groups (Hendricks et al 2019). This is a cultural phenomenon however, and it has been noted by some as a feature of Western medicine (not for example, traditional Chinese medicine) (Khalid, 2008, Hendricks et al 2019).

Speaking in metaphors however can have unintended consequences. There are reports that show that the framing of language of study participants can be consistent with the metaphors to which they are exposed (Hendricks et al, 2019). The metaphor of a country as a body can cause association of pathogens with immigrants, thereby negatively framing participant opinion of immigrants (Landau et al, 2009). With respect to healthcare, metaphorical framing of cancer as an enemy with whom one does battle can influence patient choice towards overly aggressive cancer treatments (Hauser and Schwarz, 2015). Khalid (2008) argues for 'demilitarising' breast cancer as a disease, as the military metaphor can be viewed as a 'masculinised' notion that ultimately alienates women from their own body (cancer cells do not emanate from an external source, which an enemy presumably would). This battle with cancer reduces women to a binary in which they are either victors or defeated - survivors or victims (Khalid 2008). As the progress of cancer is not in the power of the 'victims', it is not viewed as a fair representation of the struggle women with breast cancer undergo, as it suggests then that defeat is a personal failing (Hendricks et al 2019). Granger mentioned in an article in *The Guardian* in 2014: "*I do not want to feel a failure about something beyond my control. I refuse to believe my death will be because I didn't battle hard enough.*"

Recent studies suggest that cancer as a journey is a more appropriate metaphor than the military one (Hendricks et al 2019). Although the clinicians that I recruited did not explicitly reference battles or survivorship (in fact they spoke more of journeys), these references may have been picked up by the women I studied from their breast surgeon, oncologist, friends, family or media. Regardless of the origin of the military metaphor, I have argued earlier in this chapter that it may amplify risk perception and contribute to decisions for implant-based reconstruction and even CPM. If metaphorical framing underpins women's decision-making towards these procedures, it may perhaps be more beneficial to women to learn to identify and priorities their personal values, before choosing a procedure. This may be of particular importance to those requesting CPM, as metaphorical framing in this case may contribute to a desire for additional surgery, which is generally not deemed necessary from an oncological perspective. The quickly discounted 'foreign body' by four participants is also reminiscent of Emily Martin's discussion of the 'body as nation' metaphor in descriptions of the immune system (1990), which could contribute to women's pejorative views of breast implants.

Williams Camus (2009) described three functions of metaphor in cancer research based on reports in newspapers: attracting the reader, structuring and explaining scientific concepts, and organising the text into narratives. Although the clinicians I studied did not make reference to use of metaphor during consultations, I suggest that clinicians may use particular language that performs the same function as metaphor, and can in part influence women's choice.

Appleton and Flynn (2014) suggested that language is a unique individual experience and that there may be a difference between medical professional and patient understanding of cancer language and metaphor. My findings suggest that when a reconstruction is defined as 'natural', it may steer certain women towards an autologous reconstruction (see sections 6.2 and 6.3); 'natural' is a value-based description. As autologous reconstruction represents major, invasive surgery, care must be taken when using such language.

It is not easily possible to identify the origins of the *natural* narrative in discussions of breast reconstruction. Delineating whether it originates with medical professionals or if it is language adopted by clinicians in an effort to utilise language that women find familiar is beyond the scope of this study. Five of the six clinicians made reference to the autologous reconstruction as being natural, with one plastic surgeon and two breast care nurses at Site 1 stating it is the ideal reconstructive type. Recall that participant C104 stated that autologous reconstruction is the most *natural* reconstruction for the breast, and this was a belief that was ingrained in the British plastic surgery training programme. However, one surgeon at Site 2 described women presenting with either two initial preferences: "*a quick fix or I want a breast that's longer lasting, the most natural I can have*" (C201 – OPBS). The findings from the women and clinicians recruited to this study suggest that women likely initiate discussion of what is 'natural'; it is however language that is at least perpetuated by clinicians.

Apart from usage of the word natural, other words that could be seen as loaded or weighted were used by clinicians during the interviews. For example, C104 mentioned: "*…I have seen failure of implant reconstructions after crippling months or years of complications such as capsular contracture…"*. This clinician utilised persuasive language, describing implant reconstruction as crippling, and a failure; the clinician had previously described autologous reconstruction as the most *appropriate* type of reconstruction. Use of such language could easily sway the typical patient.

In this section, I have expanded upon clinician communication and its role in decision-making. I have already established the role of trust in the surgeon as well as preference of the surgeon in decision-making. This section adds to these findings, exploring how metaphors, narratives and language can also influence women's decision-making in breast reconstruction.

6.9 Contribution to the Literature and Recommendation for Clinical Practice

The primary contribution of this study to the existing body of research is a greater insight into the decision-making of women choosing a type of breast reconstruction. Three approaches to *Caring for the Body* were developed, which suggest that the women in this study generally chose a type of reconstruction based one or more of the following: personal values or beliefs about a type of reconstruction (*Preference for the Natural*), their perception of the risk associated with a reconstruction (*Perceptions of Risk*) and practical concerns (*A Practical Decision*). Women may also be influenced, in part or completely, by their reconstructive surgeon, which is especially significant as some clinicians expressed a preference for certain types of reconstruction. I do not suggest that all women's motivations for breast reconstruction are represented by the three approaches that constitute *Caring for the Body*. I simply offer narratives that may provide clinicians and researchers greater insight into the complexities of breast reconstruction decision-making, as experienced by the women in this study.

Another contribution to the literature includes the moral discourse expressed by the women of *The Real and Reconstituted Body,* which guided their choice of autologous reconstruction. They made their decision based on a pejorative view of breast implants, given their association with cosmetic surgery, as well as a perception of inherent value in utilising their own tissue for reconstruction. For these women, implant-based reconstruction was akin to vanity improvement, representing a shift from when cancer represented a virtuous reason for having a breast implant. This shift may be explained by a change in cultural breast cancer narratives; the once common, heroic, battlefield narrative of breast cancer may have held less resonance with these women than the newer one, a narrative of positive personal transformation. It must be stressed that these were the views of a small group of women.

For the women in this study of South Asian heritage, I suggested an underlying 'good woman' narrative, which was one of non-disclosure to the local cultural community, whilst privately subverting cultural norms by engaging in breast reconstruction. Such secrecy occurred in a bid to prevent being socially stigmatised, perhaps linked to concerns of cancer as ‘deserved’ due to moral failing, or as an inheritable disease, which has been reported elsewhere (Bedi and Devins 2016). There were also concerns that knowledge of reconstruction would draw attention to the reconstructed breast as sexualised, as opposed to rehabilitated, and therefore they chose to disclose neither cancer nor reconstruction. The ‘good woman’ therefore upheld personal and family honour, but also voiced ideals of bravery and heroism for privately undertaking breast reconstruction despite cultural norms. This extension of perceived cultural stigma from breast cancer to breast reconstruction is another contribution to the literature, which could link to the reduced uptake of reconstruction in South Asian women (Bedi and Devins, 2016).

A significant contribution of this study to the literature is the importance of risk perception and its role in decision-making in breast reconstruction. Risk perception was clearly linked to choice of different types of reconstruction, and a woman’s approach to risk was central to this decision. I have explored various theories that may explain how women approach/perceive risk, and furthermore situations which can modulate risk perception, notably the affect heuristic. Perhaps most interesting to understanding decision-making is the mechanism I suggested earlier in this chapter, that some women may choose a reconstruction based on an emotion to a salient aspect of a reconstruction, and then rationalise their decision *after* this – this rationalisation can be risk-based, or for some, moral.

There did seem to be variation (or even bias) in risk communication. This may be a consequence of clinicians having a preference for a particular procedure, an important finding that has been reported elsewhere (ie Potter et al, 2013). Other factors may contribute to this, for example, the evidence suggests that clinician assessment of risk is far from standardised, which would influence how clinicians communicate risk. Clinician risk assessment may also be affected by cognitive bias, just as patients are. The language used by clinicians may also be of significance - their use of metaphor and ‘loaded’ words in risk communication may modulate women’s risk perception. For women who are ‘*Salient - Instant/Immediate decision-makers’* (Harcourt and Rumsey, 2004), the importance of the reflective surgeon is paramount – particular words and metaphors can engender affinity or disdain towards particular procedures that for certain women can be difficult to ignore.

With this in mind, my recommendation for clinical practice is that if breast reconstruction consultations are to be individualised and truly patient-centred, the communication of risk should be standardised. This will reduce the possibility of clinicians highlighting selected risks, omitting discussion of certain risks, or using risk as a negotiation tool. Consequently, women's perception of risk may be less influenced and they then may be better supported to choose the procedure that best suits their needs. There are a number of ways to operationalise this. Firstly, materials such as standardised forms (endorsed by professional bodies) could be developed for surgeons and for women, which would outline the latest evidence of comparative risks for relevant complications, by reconstructive procedure offered. This could include quantified risks if they are in a format that is accessible to less numerate women, and outline major risks such as reconstructive failure. Current major patient information leaflets, including the *BAPRAS guide to breast reconstruction,* Macmillan's *Understanding Breast Reconstruction,* and leaflets from some major hospitals, do not offer comparative risks, which may impede women from making a truly informed choice. Materials, such as sample videos, could also be distributed amongst surgeons, giving concrete examples of how a fair offer of reconstructive procedures may be conducted.

Secondly, clinical updates at conferences and courses could be offered, explaining the importance of risk communication, outlining how risk is interpreted and modulated by women, and highlight its importance as a critical component of patient-centred care and surgical shared decision-making. Literature or speakers at these educational events could also encourage surgeons to be reflexive about possible personal preference and cognitive bias, and furthermore, instruct surgeons regarding 'cognitive debiasing' techniques (see section 6.4). This is reminiscent of an aspect of patient-centredness, recall the fifth dimension of Mead and Bower's (2000) model – 'the doctor-as-person'. Thirdly, dissemination of the findings of this study by way of publication in a journal can also inspire standardised risk communication in breast reconstruction. Lastly, collection of local performance data could identify NHS Trusts with atypical rates of the various reconstructive procedures, and these organisations could be targeted for support.

The next recommendation for clinical practice is the aspiration for a 'value-free' consultation with the surgeon. This implies the avoidance of 'big-ticket' language, such as 'natural', 'battle', and even 'gold standard'. I have explored in this chapter how words like ‘natural’ can evoke an autologous reconstructive preference, particularly when ‘natural’ holds salience with ‘*Instant/Immediate decision-makes’* (Harcourt and Rumsey, 2004). Words that perpetuate the military metaphor, likening the journey to a battle, can inspire fear, which can modulate women’s perceptions of risk. Once ingrained, women’s perception of risk may be difficult to change. Avoiding, or reducing such language, and open exploration of what is important to the woman sitting across from them (or in the Covid era, on the other end of the phone), may support women in choosing the procedure that suits them the best. This would require the clinician to be reflexive and measured, allowing these women to show what their own language is, and then filling that space, or mirroring that wording. It is recognised that complete avoidance of this may not be (or is not) possible, as many women will initiate discussion utilising this type of language. Clinicians should in this case attempt to prevent from perpetuating these tropes as best possible, in order to promote a change in discourse towards one that has heard the individual constructions of what breast reconstruction represents to each woman. This would represent a step towards a consultation that is considerate of the complex and often conflicting tidal wave of information that women must navigate in order to make a life altering decision. It is understood that a change in language that is so ingrained in reconstructive discourse is no simple feat, so I also recommend the development of materials to help surgeons and nurses conceptualise this, particularly as it is likely that frequently conducting consultations may result in surgeons following a semi-structured script. These recommendations can improve the patient-centredness of the reconstructive consultation.

I also offer a particular recommendation based on the accounts of the South Asian women who participated in this study. These women voiced concerns regarding fatalistic beliefs held by members of their respective communities, towards breast cancer and reconstruction; this is supported by the literature (Bedi and Devins, 2016). Some of the clinicians in this study reported reduced uptake of reconstruction in South Asian women, which may be in part due to the persuasive and ingrained nature of these beliefs. A misrepresented perception of breast cancer and reconstruction may be unduly reducing uptake of intervention. In Bottorff et al’s (1998) Canadian study of South Asian women with breast cancer, they suggested that these women should be offered stories of hope and successful detection, to counter the stories of tragedy and hopelessness. The findings of this study suggest that this message should be extended to South Asian women in the UK as well.

A newer oncoplastic breast surgery guide to good practice has been devised by a collaboration between the Association of Breast Surgery (ABS) and the British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS) (Gilmour et al, 2021). Importantly, the guide no longer states that all relevant procedures should be offered with *equal* weighting. The newer guide (2021) still highlights the importance of offer of reconstruction to all women with mastectomy. Reassuringly, and in the same spirit as my recommendations, it puts further emphasis on individualised care; the authors specifically making reference to patient-centred care and shared decision-making, recommending that surgeons should make efforts to understand their patients' goals and expectations. It remains to be seen how this new guide will influence decision-making on breast reconstruction within the surgical consultation.

6.10 Strengths and Limitations

As with all research, there are both strengths and limitations of this work. The participants in this thesis provided rich and thick data which has illuminated the complexity of decision-making. Themes that were constructed through the analysis process were grounded in data from the literature. I identified understandings about breast reconstruction relating to specific cultural groups that have contributed to the literature. My work has provided deeper insight into the nuanced motivations underpinning breast reconstruction decision-making, and how women choose a type of reconstruction, both contextualising findings to the existing literature and extending understanding. Perhaps most importantly, the recommendations for future clinical practice described in the previous section may encourage reflexivity and patient-centredness in clinicians, and improve decision-making for women.

No work of this nature is without limitations. The original plan was to interview a larger number of women, including those who declined reconstruction, which could have given further insight into how clinicians discuss risk. Interview schedules did not explicitly ask for women's personal details such as age or whether they were living with a partner or not. An important component of this demographic data included sexual orientation. Although there was no mention of a same-sex relationship when partner involvement was explored (only mention of husbands), this is relevant as there are two major works exploring breast reconstruction decision-making in women in same-sex relationships, one of which found an association with women declining reconstruction (Boehmer et al 2007, Rubin and Tanenbaum, 2011).

Another limitation of this work includes the characteristics of the sites from which women and clinicians were recruited. As described in Chapter 1 (see section 1.6) there appears to be restricted access to plastic surgery in some areas. Therefore, the views of some of the women from this study may not be transferable to women from rural areas, or areas in which OPCs have a significant backlog. Also, the characteristics of the surrounding population may have affected findings. For example, if local deprivation at Site 2 encouraged selection of IBR due to concomitant ill-health, 'choices' for IBR may have actually represented the only available option. Relevant to Site 2 was the close link of IBR and CPM. Site 2 may have offered more CPM, which could have influenced findings; and therefore the reasons for the women choosing IBR may have been conflated with choosing CPM.

The reconstruction units of the recruitment sites were the most significant limitation of this study, as it became increasingly apparent during the conduct of the research that they were atypical (by which time study sites could not be changed). Four major characteristics of these sites were unusual. Firstly, two of the reconstructive surgeons interviewed, one from each site, expressed preference for particular procedures. This finding along with statements from the other interviews with breast care nurses and clinicians suggested preferences may have become embedded as site specific cultures that were contrary to national guidelines (see Section 5.3.2). With Site 2 performing roughly 90% implant-based reconstruction, and Site 1 performing largely LD flap reconstructions, neither site followed national trends that would suggest recommended best clinical practice at the time of the study. Secondly, a number of women who participated in this study, predominantly from Site 2, had undergone or were considering having CPM. Statements from national bodies representing breast surgeons do not consider CPM necessary in the absence of any pathogenic gene variant (ie BRCA1 – see Section 6.5); this is supported by Gilmour et al's recent national oncoplastic breast guidance (2021). Thirdly, the delayed-immediate approach (see Section 1.3.2) that was reportedly provided frequently at Site 2, is not meant to be routinely offered. Current national guidance (Gilmour et al, 2021) suggests that autologous reconstructions can be safely irradiated in the immediate setting from an oncological perspective; and immediate autologous reconstruction with radiotherapy has similar, or lower, complication rates than if performed in the delayed setting. Consequently, Gilmour et al (2021) recommend that immediate autologous reconstruction should still be offered to all women expected to require post mastectomy radiotherapy. Lastly, the units themselves were atypical given that their clinician configuration and procedures offered were not in keeping with the typical hub and spoke model of UK breast reconstruction services (see Sections 1.4.1 and 4.3). If centres of their size followed a typical hub and spoke model, Site 1 would not be expected to provide free flap reconstructions, and Site 2 would be expected to employ at least two surgeons offering microvascular reconstructions.

Given that the surgeons from the recruitment sites described atypical practice, this may indicate that the clinician findings outlined in this thesis may not be transferable to other clinicians/reconstruction centres working within the framework of national recommendations. Nonetheless, the clinician findings have a value in that they illuminate the complexity of decision-making and the multiple influences on women's decision making, including the impact of some surgeons and organisational culture. The small convenience sample of clinicians is a further limitation, hence the themes developed from these interviews should be interpreted with care. Despite these limitations, the effects of clinician preference on influencing decision-making has been recognised in the literature (Potter et al, 2013).

The atypical characteristics of the recruitment sites described above may also indicate that the findings from the women recruited to this study were not transferable to women at typical reconstruction centres in the UK. The unusual provision of the reconstructive service at these sites, along with the influence of surgeons who described atypical practices, would conceivably shape information provision and reconstructive consultations. A major contributor to women's decision-making is the information provided within consultations as well as surgeons themselves. Consequently, this framework representing women's decision-making as well as women's risk narratives would have been influenced by their experience at unusual centres and would be unlikely to represent decision-making at typical reconstruction centres. For example, the *Risk and the Assaulted Body* subtheme was developed from the accounts of women largely from Site 2 (with its associated site specific culture), which may have been influenced by unbalanced information regarding procedural risk. It was linked to choice of CPM, which as previously discussed, is generally not recommended in routine practice. Reconstruction units adopting recommended guidelines may find women choose differently assuming a balanced risk assessment conversation occurs. Similarly, there may be limited transferability of *The Real and Reconstituted Body* subtheme*,* as it was largely developed from the interviews of women at Site 1, where one surgeon divulged a clear preference for autologous reconstruction.

Despite the limited transferability of these findings, just as with the clinician themes they carry some value as they illuminate the complexity of women's decision-making in two UK reconstruction centres. Variations in rates of procedures has been noted in different cancer networks (Jeevan et al, 2014) suggesting that these sites may not be alone in their atypical practices, particularly given that the frequency of CPM procedures are rising in the UK (see section 6.5). The major findings of this study (ie *Caring for the Body* and *The Influence of the Surgeon*) however are well supported by the literature, and a recent exploration of how women choose particular types of breast reconstruction did highlight similar influences (Giunta et al, 2021 – see section 6.2). Nonetheless, the atypical nature of the recruitment sites in this study limits the transferability of its findings, and further exploration at more typical recruitment sites would be recommended.

6.11 Recommendations for Future Research

There are many avenues for further research based on the findings of this study. As described in the previous section, given the atypical nature of the sites, it would be worth conducting a similar study of how women choose a type of breast reconstruction, but at sites that are more reflective of a typical breast reconstruction unit. Perhaps most importantly, further research into the delivery of the reconstructive consultation itself is a major recommendation from this study. One option could be a similar study to the clinician component of this study, but across a wider range of breast reconstruction units across the country, and with many more clinicians. An exploration of how clinicians assess and communicate risk, compared to how women interpret risk, would be of particular import, as risk communication and risk perception were of significant influence to women as they chose a type of breast reconstruction. Such a study should also focus on how clinicians communicate and explain options in general, to assess whether presentation is equitable. Expanding on the findings from this study, further research should explore site specific culture and the effect of clinician preference in reconstructive consultations. A socio-linguistic assessment of the language used in surgical consultations would also make an interesting study, as I have proposed that weighted language can contribute to women's decision-making and risk perception.

Although the more sociological contributors to women's decision-making influenced fewer women in this study, nonetheless qualitative researchers may wish to pursue these avenues as well. A further exploration of women who decline reconstruction could be warranted, to assess how risk is perceived in their decision-making. A specific investigation of breast reconstruction in a larger sample of South Asian and other minority groups should be undertaken in order to explore the different narratives behind choosing reconstruction (including type), declining reconstruction, and potential isolation within their different communities. An examination of the impact of breast reconstruction support groups on choice of type of breast reconstruction would be pertinent to reconstructive services across the country, including both online and local groups. An investigation of the association between CPM and type of reconstructive choice would be valuable, to better understand women's choices.

6.12 Conclusion

In this thesis I have explored the research question: *What do women perceive as influential when choosing a type of breast reconstruction?* Through analysis of the interviews of the women, two major themes were established, which represent influences on the decision-making of women, towards a particular type of breast reconstruction: *Caring for the Body* and *The Influence of the Surgeon.* The former represented three approaches to caring for the body expressed by the women of this study, which directly contributed to choice of type of reconstruction. These approaches outlined how the women in this study generally chose a type of reconstruction based on personal preference, perception of risk and practicality.

Through analysis of the interviews of clinicians, I identified a different set of themes that were perceived as influential when women chose a type of breast reconstruction: *Trust, The Clinician's Preference,* and *Clinical Restrictions on Choice.* There was a clear difference in the findings compared to the women interviewed, suggesting that this study has identified contributors to decision-making that were not previously appreciated as influential by these clinicians. Importance was noted in the language utilised by some consultants, identifying loaded words such as 'natural', and how language is often adopted by patients. One consultant noted that compromise was at the heart of the breast reconstruction decision, which did not seem to be reflected in the decision-making of the women who were studied.

The primary contribution of this study is the identification of the central role that the perception and communication of risk plays as women choose a type of breast reconstruction. This led to the recommendation for clinical practice, that the communication of risk should be standardised, and that clinicians should be reflexive and measured, to prevent usage of words and metaphors that can unduly precipitate a choice of type of breast reconstruction. I believe that this can reduce the effect of biased communication and preference of clinicians on women's decision-making, and empower them to make the choice that best suits their needs. I suspect this may also improve unwarranted variation in the provision of particular types of reconstruction, as it may provide a counter for some women to site specific culture and consultant preference. Ultimately, when women make better quality decisions for their personal needs, this will improve their satisfaction with breast reconstruction and quality of life, which is the underlying purpose of breast reconstruction in itself.

REFERENCES

1. Abrams, R.D. and Finesinger, J.E. (1953), Guilt reactions in patients with cancer. Cancer, 6: 474-482.

2. Abu-Nab Z and Grunfeld EA (2007) Satisfaction with outcomes and attitudes towards scarring among women undergoing breast reconstructive surgery. Patient Education and Counselling. 66(2):243-249

3. Agarwal S, Kidwell K, Kraft C, Kozlow J, Sabel M, Chung K, Momoh A (2015) Defining the Relationship between Patient Decisions to Undergo Breast Reconstructions and Contralateral Prophylactic Mastectomy. Plastic and Reconstructive Surgery. 135(3): 661-670

4. Ager, B., Butow, P., & Jansen, J. (2016). Contralateral prophylactic mastectomy (CPM): A systematic review of patient reported factors and psychological predictors influencing choice and satisfaction. *Breast J*, *28*, 107–120. doi:10.1016/j.breast.2016.04.005.

5. Al-Ghazal SK, Fallowfield L, Blamey RW (2000) Comparison of psychological aspects and patient satisfaction following breast conserving surgery, simple mastectomy and breast reconstruction. European Journal of Cancer. 36(15); 1938-1943

6. Al-Ghazal SK, Sully L, Fallowfield L, Blamey RW (2000) The psychological impact of immediate rather than delayed breast reconstruction. European Journal of Surgical Oncology. 26 (1); 17-19

7. Albornoz CR, Bach PB, Mehrara BJ, Disa JJ, Pusic AL, McCarthy CM, Cordeiro PG, Matros E. A paradigm shift in U.S. breast reconstruction: increasing implant rates. 2013. Plastic and Reconstructive Surgery: 131 (1): 15-23

8. Allen RJ, Treece P. Deep inferior epigastric perforator flap for breast reconstruction. *Ann Plast Surg*. 1994;32(1):32-38. doi:10.1097/00000637-199401000-00007

9. Altman DG, Schulz KF, Moher D, et al. The Revised CONSORT Statement for Reporting Randomized Trials: Explanation and Elaboration. Ann Intern Med.2001;134:663-694.

10. Ames, H., Glenton, C. & Lewin, S. Purposive sampling in a qualitative evidence synthesis: a worked example from a synthesis on parental perceptions of vaccination

communication. *BMC Med Res Methodol* **19,** 26 (2019). https://doi.org/10.1186/s12874-019-0665-4

11. Anderberg D, Chevalier A, Wadsworth J (2010) Anatomy of a health scare: Education, income and the MMR controversy in the UK. *Journal of Health Economics*. 30(3); 515-530

12. Appleton L and Flynn M (2014) Searching for the new normal: Exploring the role of language and metaphors in becoming a cancer survivor. *European Journal of Oncology Nursing*. 18(4); 378-384

13. Ashfaq, A., McGhan, L.J., Pockaj, B.A. *et al.* Impact of Breast Reconstruction on the Decision to Undergo Contralateral Prophylactic Mastectomy. *Ann Surg Oncol* **21,** 2934–2940 (2014).

14. Astin, J. A. (1998). Why patients use alternative medicine: results of a national study. *jama*, *279*(19), 1548-1553.

15. Ayton JE, Tesch L, Hansen E. Women's experiences of ceasing to breastfeed: Australian qualitative study. BMJ Open 2019;9:e026234. doi:10.1136/ bmjopen-2018-026234

16. Bakker D, Fitch M, Gray B, Reed E, Bennet J (2001) Patient-health care provider communication during chemotherapy treatment: The perspectives of women with breast cancer. Patient education and counselling. 43(1); 61-71

17. Balint E (1969) The possibilities of patient-centred medicine. J R Coll Gen Pract 17 (82); 269-276

18. Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—The pinnacle patient-centered care.

19. Bastian, H., Glasziou, P., & Chalmers, I. (2010). Seventy-five trials and eleven systematic reviews a day: how will we ever keep up?. *PLoS medicine*, *7*(9), e1000326. https://doi.org/10.1371/journal.pmed.1000326

20. Bedi M and Devins GM (2016). Cultural considerations for South Asian women with breast cancer. *J Cancer Surviv*. 10:31-50

21. Beesley H, Holcombe C, Brown SL, Salmon P (2013) Risk, worry and cosmesis in decision-making for contralateral risk reducing mastectomy: Analysis of 60

consecutive cases in a specialist breast unit. The Breast. 22(2);179-184

22. Begum S, Grunfeld E, Ho-Asjoe M, Farhadi J (2011) An exploration of patient-decision making for autologous breast reconstructive surgery following a mastectomy. Patient education and counselling. 84; 105-110

23. Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, *26*(13), 1802–1811. https://doi.org/10.1177/1049732316654870

24. Bishop FL, Yardley L, Lewith G (2005) Developing a measure of treatment beliefs: The complementary and alternative medicine beliefs inventory. *Complementary Therapies in Medicine*. 13(2); 144-149

25. Blackburn NE, McVeigh JG, McCaughan E, Wilson M (2018) The musculoskeletal consequences of breast reconstruction using the latissimus dorsi muscle for women following mastectomy for breast cancer: A critical review. Eur J Cancer Care. 27(2);e12664

26. Blumer, H. (1954). What is wrong with social theory?. *American sociological review*, *19*(1), 3-10.

27. Boehmer U, Linde R, Freund K (2007) Breast Reconstruction following Mastectomy for Breast Cancer: The Decisions of Sexual Minority Women. Plastic and Reconstructive Surgery. 119(2); 464-472

28. Booth A., Noyes J, Flemming K, Gerhardus A., Wahlster P., Van der Wilt G.J., Mozygemba K., Refolo P., Sacchini D., Tummers M., Rehfuess E. (2016) Guidance on choosing qualitative evidence synthesis methods for use in health technology assessments of complex interventions [Online]

29. Booth A, Noyes J, Flemming K*, et al* Formulating questions to explore complex interventions within qualitative evidence synthesis *BMJ Global Health* 2019; **4:**e001107.

30. Bottorff JL, Johnson JL, Bhagat R et al (1998) Beliefs related to breast health practices: the perceptions of South Asian women living in Canada. Social Sci Med. 47(12); 2075-2084

31. Boughey, J.C., Attai, D.J., Chen, S.L. *et al.* Contralateral Prophylactic Mastectomy (CPM) Consensus Statement from the American Society of Breast

Surgeons: Data on CPM Outcomes and Risks. *Ann Surg Oncol* **23,** 3100–3105 (2016).

32. Bradbury-Jones, C. (2007). Enhancing rigour in qualitative health research: exploring subjectivity through Peshkin's I's. *Journal of advanced nursing*, *59*(3), 290-298.

33. Bradbury-Jones C, Jenna Breckenridge, Maria T. Clark, Oliver R. Herber, Christopher Wagstaff & Julie Taylor (2017): The state of qualitative research in health and social science literature: a focused mapping review and synthesis, International Journal of Social Research Methodology

34. Bramley M, Barber M, Fowler C, Grimsey E, Hu J, MacNeill F, Drew P, Benson J, Roche N, Gandhi A. (2017) Association of Breast Surgery Summary Statement. Contralateral Mastectomy for Unilateral Breast Cancer.

35. Braun V and Clarke V (2006) Using thematic analysis in psychology. Qualitative research in psychology. 3:77-101

36. Braun V and Clarke V (2013) *Successful Qualitative Research: A Practical Guide for Beginners*

37. Britten N, Qualitative interviews in medical research, BMJ 1995;311:251-3

38. Britten N, Campbell R, Pope C. Using meta ethnography to synthesise qualitative research: a worked example. (2002). Journal of Health Services Research & Policy, 7(4), 209–215. https://doi.org/10.1258/135581902320432732

39. Bruera, E., Willey, J. S., Lynn Palmer, J., & Rosales, M. (2002). Treatment decisions for breast carcinoma: patient preferences and physician perceptions. *Cancer*, *94*(7), 2076-2080.

40. Buus, N., & Agdal, R. (2013). Can the use of reporting guidelines in peer-review damage the quality and contribution of qualitative health care research?. *International journal of nursing studies*, *50*(10), 1289-1291.

41. Buus, N., & Perron, A. (2020). The quality of quality criteria: Replicating the development of the Consolidated Criteria for Reporting Qualitative Research (COREQ). *International journal of nursing studies*, *102*, 103452.

42. Burgess RG (1984) In the Field: An Introduction to Field Research. London, Unwin Hyman.

43. Caelli K, Ray L, Mill J. 'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research. *International Journal of Qualitative Methods*. June 2003:1-13. doi:10.1177/160940690300200201

44. Callahan C MSW, LCSW-C (2005) Facial Disfigurement and Sense of Self in Head and Neck Cancer, Social Work in Health Care, 40:2, 73-87,

45. Cancer Research UK – Breast Cancer statistics Sept 2019

46. Carbine NE, Lostumbo L, Wallace J, Ko H. Risk-reducing mastectomy for the prevention of primary breast cancer. Cochrane Database of Systematic Reviews 2018, Issue 4.

47. Carlson, G. W., Bostwick, J., 3rd, Styblo, T. M., Moore, B., Bried, J. T., Murray, D. R., & Wood, W. C. (1997). Skin-sparing mastectomy. Oncologic and reconstructive considerations. *Annals of surgery*, *225*(5), 570–578. https://doi.org/10.1097/00000658-199705000-00013

48. Carroll C. Qualitative evidence synthesis to improve implementation of clinical guidelines. BMJ. 2017 Jan 16;356:j80. doi: 10.1136/bmj.j80. PMID: 28093384.

49. Cemal Y, Albornoz CR, Disa JJ, McCarthy CM, Mehrara BJ, Pusic AL, Cordeiro PG, Matros E (2013) A paradigm shift in US breast reconstruction: Part 2. The influence of changing mastectomy patterns on reconstructive rate and method. Plastic and Reconstructive Surgery. 131(3):320e-6e

50. Chang LV (2018) Information, education, and health behaviors: Evidence from the MMR vaccine autism controversy. *Health Economics*. 27; 1043-1062

51. Charles, C., Gafni, A. and Whelan, T., 1997. Shared decision-making in the medical encounter: what does it mean?(or it takes at least two to tango). *Social science & medicine*, *44*(5), pp.681-692.

52. Chen H, Zhang P, Zhang M, Wang M, Bai F, Wu K (2019) Growing Trends of Contralateral Prophylactic Mastectomy and Reconstruction in Young Breast Cancer. Journal of Surgical Research. 239; 224-232

53. Cheng T, Causarano N, Platt J, Jones JM, Hofer SOP, O'Neill AC, Zhong T | Carter J (Reviewing editor) (2018) Restoring wholeness: Women's embodied experiences in considering post-mastectomy delayed breast reconstruction, Cogent Social Sciences, 4:1, DOI: 10.1080/23311886.2018.1479478

54. Chewning, B., Bylund, C. L., Shah, B., Arora, N. K., Gueguen, J. A., & Makoul, G. (2012). Patient preferences for shared decisions: a systematic review. *Patient education and counseling*, *86*(1), 9-18.

55. Clayman, M. L., Makoul, G., Harper, M. M., Koby, D. G., & Williams, A. R. (2012). Development of a shared decision making coding system for analysis of patient–healthcare provider encounters. *Patient education and counseling*, *88*(3), 367-372.

56. Cobb S and Starr S (2012) Breast cancer, breast surgery, and the makeover metaphor. *Social Semiotics*. 22(1); 83-101

57. Cohen, I. K. (1994). Impact of the FDA ban on silicone breast implants. *Journal of Surgical Oncology, 56(1), 1–1.* doi:10.1002/jso.2930560102

58. Colvin, C.J., Garside, R., Wainwright, M. *et al.* Applying GRADE-CERQual to qualitative evidence synthesis findings—paper 4: how to assess coherence. *Implementation Sci* **13,** 13 (2018). https://doi.org/10.1186/s13012-017-0691-8

59. Cooke A, Smith D, Booth A. Beyond PICO: The SPIDER Tool for Qualitative Evidence Synthesis. *Qualitative Health Research*. 2012;22(10):1435-1443. doi:10.1177/1049732312452938

60. Coulter A and Collins A (2011) Making shared decision-making a reality: No decision about me, without me. The King's Fund.

61. Covelli, A.M., Baxter, N.N., Fitch, M.I. *et al.* 'Taking Control of Cancer': Understanding Women's Choice for Mastectomy. *Ann Surg Oncol* **22,** 383–391 (2015).

62. Coyne I (1997) Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? Journal of Advanced Nursing. 26; 623-630

63. Creswell, J. W. (2013). Qualitative inquiry and research design: Choosing among five approaches (3rd ed.). Thousand Oaks, CA: Sage

64. Critical Appraisal Skills Programme (2018). CASP (Qualitative Checklist) [online] Available at: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-

Checklist-2018.pdf. Accessed: 13/09/2020

65. Crompvoets S (2006) Comfort, Control, or Conformity: Women Who Choose Breast Reconstruction Following Mastectomy, Health Care for Women International, 27:1, 75-93, DOI: 10.1080/07399330500377531

66. Croskerry P, Singhal G, Mamede S; Cognitive debiasing 1: origins of bias and theory of debiasing; *BMJ Quality & Safety* 2013;**22:**ii58-ii64.

67. Crotty M (1998), The Foundations of Social Research: Meaning and Perspective in the Research Process. Los Angeles, CA: SAGE

68. Cutress RI, Summerhayes C and Rainsbury R (2013) Guidelines for oncoplastic breast reconstruction. *The Annals of The Royal College of Surgeons of England*, 95(3), pp. 161–162

69. d'Agincourt-Canning L (2005) The Effect of Experiential Knowledge on Construction of Risk Perception in Hereditary Breast/Ovarian Cancer. Journal of Genetic Counselling. 14(1)

70. Dare, S., Mackay, D. F., & Pell, J. P. (2015). Relationship between smoking and obesity: a cross-sectional study of 499,504 middle-aged adults in the UK general population. *PloS one*, *10*(4), e0123579.

71. Davies PG, Patient centredness. *Journal of Epidemiology & Community Health* 2007;**61:**39.

72. Delaney LJ (2018) Patient-centred care as an approach to improving health care in Australia. *Collegian.* 25(1); 119-123

73. Denford S, Harcourt D, Rubin L, Pusic A. Understanding normality: A qualitative analysis of breast cancer patients concepts of normality after mastectomy and reconstructive surgery. Psycho-Oncology. 2011; 20; 553-558

74. Department of Health, NHS Medical Directorate. Poly Implant Prothese (PIP) Breast Implants: Final Report of the Working Group. 2012.

75. Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: A review of possible methods. *Journal of Health Services Research & Policy*, *10*(1), 45–

53. https://doi.org/10.1177/135581960501000110

76. Elston DM (2020) Confirmation bias in medical decision-making. J Am Acad Dermatol 82:572.

77. Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., ... & Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of general internal medicine*, *27*(10), 1361-1367.

78. Elwyn G, Tilburt MD, Montori VM. (2013) The ethical imperative for shared decision-making. *European Journal for Person Centered Healthcare.* 1(1); 129-131

79. Fang SY, Shu BC, Chang YJ (2013) The effect of breast reconstruction surgery on body image among women after mastectomy: A meta-analysis. *Breast Cancer Research and Treatment*. 137; 13-21

80. Feng Y, Flitcroft K, van Leeuwen M, Elshaug A, Spillane A, Pearson S-A (2019) Patterns of immediate breast reconstruction in New South Wales Australia: a population-based study. ANZ J Surg. 89(10): 1230-1235

81. Fertsch, S., Munder, B., Hagouan, M., Schulz, T., Thamm, O., Stambera, P., ... & Andree, C. (2017). Immediate-DElayed AutoLogous (IDEAL) breast reconstruction with the DIEP flap. *Chirurgia (Bucur)*, *112*(4), 387-393.

82. Filipe MD, Siesling S, Vriens MR, van Diest PJ, Witkamp AJ,Mureau MAM ,Socioeconomic status significantly contributes to the likelihood of immediate postmastectomy breast reconstruction in the Netherlands: A nationwide study, European Journal of Surgical Oncology, Volume 47, Issue 2, 2021

83. Flemming, K., Booth, A., Garside, R., Tunçalp, Ö., & Noyes, J. (2019). Qualitative evidence synthesis for complex interventions and guideline development: clarification of the purpose, designs and relevant methods. *BMJ global health*, *4*(Suppl 1), e000882. https://doi.org/10.1136/bmjgh-2018-000882

84. Flemming and Noyes (2021) Qualitative Evidence Synthesis: Where Are We At? *International Journal of Qualitative Methods.* 20;1-13

85. Flitcroft, K., Brennan, M., & Spillane, A. (2017). Making decisions about breast reconstruction: a systematic review of patient-reported factors influencing choice. *Quality of Life Research*, *26*(9), 2287-2319.

86. Flitcroft, K. L., Brennan, M. E., & Spillane, A. J. (2019). The impact on Australian women of lack of choice of breast reconstruction options: A qualitative study. *Psycho-oncology*, *28*(3), 547-552.

87. Flynn KE, Smith MA, Varness D (2006) A typology of preferences for participation in healthcare decision making. *Social Science and Medicine.* 63(5); 1158-1169

88. Gallagher P, Buckmaster A, O'Carroll S, Kiernan G, Geraghty J (2010), External breast prostheses in post-mastectomy care: women's qualitative accounts. Eur J Cancer Care. 19(1); 61-71

89. Gerteis M, Edgman-Levitan S, Daley J, Delbanco T (1993) *Through the Patient's Eyes: Understanding and Promoting Patient-Centred Care*. Jossey-Bass, San Francisco.

90. Gilmour, A., Cutress, R., Gandhi, A., Harcourt, D., Little, K., Mansell, J., ... & Martin, L. (2021). Oncoplastic breast surgery: A guide to good practice. *European Journal of Surgical Oncology*.

91. Gimlin, Debra L. 2000. "Cosmetic Surgery: Beauty as Commodity." Qualitative Sociology 23:77–98.

92. Glaser, B. G. & Strauss, A. 1967. The discovery of grounded theory: strategies for qualitative research. Chicago, Ill: Aldine Pub. Co.

93. Glaus SW, Carlson GW (2009) Long-term Role of External Breast Prostheses After Total Mastectomy. The Breast Journal. 15(4); 385-393

94. Glenton, C., Carlsen, B., Lewin, S. *et al.* Applying GRADE-CERQual to qualitative evidence synthesis findings—paper 5: how to assess adequacy of data. *Implementation Sci* **13,** 14 (2018). https://doi.org/10.1186/s13012-017-0692-7

95. Goffman, E. (1963) Stigma: Notes on Management of Spoiled Identity. Englewood Cliffs, NJ: Prentice-Hall.

96. Gopie J, Hilhorst M, Kleijne A, Timman R, Menke-Pluymers M, Hofer S, Mureau M, Tibben A (2011) Women's motives to opt for either implant or DIEP-flap breast reconstruction. 64; 1062-1067

97. Gopie J, Timman R, Hilhorst M, Hofer S, Mureau M, Tibben A (2011) Information-seeking behaviour and coping style of women opting for either implant or DIEP-flap

breast reconstruction. Journal of Plastic, Reconstructive and Aesthetic Surgery. 64; 1167-1173

98. Granger K (2014). “Having cancer is not a fight or battle,” *The Gaurdian,* 25 April, available at https://www.theguardian.com/society/2014/apr/25/having-cancer-not-fight-or-battle. Accessed 13 09 2021.

99. Greener JR, Bass SB & Lepore SJ (2018) Contralateral prophylactic mastectomy: A qualitative approach to exploring the decision making process, Journal of Psychosocial Oncology, 36:2, 145-158, DOI: 10.1080/07347332.2017.1395940

100. Grewal S, Bottorff J, Hilton BA (2005) The Influence of Family on Immigrant South Asian Women’s Health. *Journal of Family Nursing*. 11(3); 242-263

101. Guest G, Bunce A, Johnson L (2006) How Many Interviews Are Enough? An Experiment with Data Saturation and Variability. Field Methods. 18(1); 59-82

102. Gurm B, Stephen J, MacKenzie G, Doll R, Barroetavena M, Cadell S (2008) Understanding Canadian Punjabi-Speaking South Asian women’s experience of breast cancer: A qualitative study. International Journal of Nursing Studies. 4(2); 266-276

103. Harcourt D, Rumsey N. Mastectomy patients decision-making for or against immediate breast reconstruction. Psycho-Oncology. 2004; 13; 106-115

104. Harcourt D, Rumsey N. Psychological aspects of breast reconstruction: a review of the literature. Journal of Advanced Nursing. 2001. 35(4); 477-487

105. Harden A, Garcia J, Oliver S*, et* al Applying systematic review methods to studies of people’s views: an example from public health research *Journal of Epidemiology & Community Health* 2004;**58:**794-800.

106. Hauser DJ, Schwarz N. The War on Prevention: Bellicose Cancer Metaphors Hurt (Some) Prevention Intentions. *Personality and Social Psychology Bulletin*. 2015;41(1):66-77. doi:10.1177/0146167214557006

107. Hendricks RK, Demjén Z, Semino E & Boroditsky L (2019) Emotional Implications of Metaphor: Consequences of Metaphor Framing for Mindset about Cancer, Metaphor and Symbol, 33:4, 267-279, DOI: 10.1080/10926488.2018.1549835

108. Henninger S, Spencer B, Pasche O (2019) Deciding whether to consult the GP or an emergency department: A qualitative study of patient reasoning in Switzerland.

European Journal of General Practice. 25(3); 136-142

109. Hillen, M.A., de Haes, H.C.J.M. and Smets, E.M.A. (2011), Cancer patients' trust in their physician—a review. Psycho-Oncology, 20: 227-241

110. Holland J. History of Psycho-Oncology: Overcoming Attitudinal and Conceptual Barriers. Psychosomatic Medicine. 2002; 64(2); 206-221

111. Holland F, Archer S, Montague J (2014) Younger women's experiences of deciding against delayed breast reconstruction post-mastectomy following breast cancer: An interpretative phenomenological analysis. Journal of Health Psychology. 1-12

112. House of Commons Public Accounts Committee – Third Report.Skills for Life: Progress in Improving Adult Literacy and Numer-acy. 2008. Available at http://www.publications.parliament.uk/pa/cm200809/cmselect/cmpubacc/154/15403.htm

113. Hume, D. An enquiry concerning the principles of morals. La Salle, Illinois: Open Court, 1960 (originally published in 1751).

114. Inhestern, L., Bergelt, C. When a mother has cancer: strains and resources of affected families from the mother's and father's perspective - a qualitative study. *BMC Women's Health* **18,** 72 (2018). https://doi.org/10.1186/s12905-018-0562-8

115. Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century: National Academy Press, 2001

116. Izett-Kay, ML, Lumb, C, Cartwright, R, Kupelian, AS, Cutner, AS, Jackson, S, Price, N, Vashisht, A. 'What research was carried out on this vaginal mesh?' Health-related concerns in women following mesh-augmented prolapse surgery: a thematic analysis. *BJOG* 2021; 128: 131– 139.

117. Janz, N. K., Wren, P. A., Copeland, L. A., Lowery, J. C., Goldfarb, S. L., & Wilkins, E. G. (2004). Patient-physician concordance: preferences, perceptions, and factors influencing the breast cancer surgical decision. *Journal of clinical oncology*, *22*(15), 3091-3098.

118. Jeevan, R. (2020). Reconstructive utilisation and outcomes following mastectomy surgery in women with breast cancer treated in England. *The Annals of The Royal College of Surgeons of England*, *102*(2), 110-114.

119. Jeevan R, Cromwell D, Browne J, Caddy C, Pereira J, Sheppard C, Greenaway K, van der Meulen J. Findings of a national comparative audit of mastectomy and breast reconstruction surgery in England. Journal of Plastic, Reconstructive and Aesthetic Surgery 2014; 67(10): 1333-44

120. Johnson JL, Bottorff JL, Balneaves LG, Grewal S, Bhagat R, Hilton, BA, Clarke H (1999) South Asian womens' views on the causes of breast cancer: images and explanations. *Patient Education and Counselling.* 37(1999); 243 - 254

121. Kahlke, R. M. (2014). Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. *International Journal of Qualitative Methods*, 37–52.

122. Kaller S, Mays A, Freedman L, Harper C, Biggs M (2020) Exploring young women's reasons for adopting intrauterine or oral emergency contraception in the United States: a qualitative study. BMC Women's Health. 20 (15)

123. Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of advanced nursing*, *72*(12), 2954-2965.

124. Kankam, H. K., Hourston, G. J., Fopp, L. J., Benson, J. R., Benyon, S. L., Irwin, M. S., ... & Malata, C. M. (2018). Trends in post-mastectomy breast reconstruction types at a breast cancer tertiary referral centre before and after introduction of acellular dermal matrices. *Journal of Plastic, Reconstructive & Aesthetic Surgery*, *71*(1), 21-27.

125. Khajuria A, Smith O, Prokopenko M, Greenfield M, Mosahebi A (2017) Protocol for a systematic review and meta-analysis on the clinical outcomes and cost of deep inferior epigastric perforator (DIEP) flap versus implants for breast reconstruction. Syst Rev. 6;232

126. Khalid JR (2008) Demilitarizing Disease: Ambivalent Warfare and Audre Lorde's "The Cancer Journals". *African American Review.* 42(3/4); 697-714

127. Kitson A, Marshall A, Bassett K, Zeitz K. (2012) What are core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing.* 69(1); 4-15

128. Kitzinger, J. (1994). The methodology of focus groups: the importance of interaction between research participants. *Sociology of health & illness*, *16*(1), 103-121.

129. Kokosis G, Khavanin N, Nahabedian M. Latissimus Dorsi Musculocutaneous Flap for Complex Breast Reconstruction: Indications, Outcomes and a Proposed Algorithm. Plastic and Reconstructive Surgery Global Open. 2019; 7(8); e2382

130. Kronowitz, S.J. and Kuerer, H.M. (2006), Advances and surgical decision-making for breast reconstruction. Cancer, 107: 893-907.

131. Kvale, S. (1994). *Interviews: An introduction to qualitative research interviewing*. Sage Publications, Inc.

132. Lakoff, G., & Johnson, M. (1980). The metaphorical structure of the human conceptual system. *Cognitive science*, *4*(2), 195-208.

133. Landau, M. J., Sullivan, D., & Greenberg, J. (2009). Evidence that self-relevant motives and metaphoric framing interact to influence political and social attitudes. *Psychological science*, *20*(11), 1421-1427.

134. Langberg EM, Dyhr L, Davidsen AS (2019). Development of the concept of patient-centredness – A systematic review. *Patient Education and Counseling.* 102 (7); 1228-1236

135. Lasserson TJ, Thomas J, Higgins JPT. Chapter 1: Starting a review. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). *Cochrane Handbook for Systematic Reviews of Interventions* version 6.1 (updated September 2020). Cochrane, 2021.

136. Lee CN, Dominik R, Levin CA, Barry MJ, Cosenza C, O'Connor AM, Mulley AG Jr, Sepucha KR (2010). 'Development of instruments to measure the quality of breast cancer treatment decisions'. Health Expectations, vol 13, no 3, pp 258–72.

137. Lee, C. N., Hultman, C. S., & Sepucha, K. (2010). What are patients' goals and concerns about breast reconstruction after mastectomy?. *Annals of plastic surgery*, *64*(5), 567-569.

138. Lee JA, Ungar S. A Coding Method for the Analysis of Moral Discourse. *Human Relations*. 1989;42(8):691-715. doi:10.1177/001872678904200803

139. Légaré, F., Ratté, S., Gravel, K., & Graham, I. D. (2008). Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient education and counseling*, *73*(3),

526-535.

140. Lewin S, Booth A, Glenton C, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. *Implement Sci*. 2018;13(Suppl 1):2. Published 2018 Jan 25. doi:10.1186/s13012-017-0688-3

141. Liberati Alessandro, Altman Douglas, Tetzlaff Jennifer, Mulrow Cynthia, Gøtzsche Pet er C, Ioannidis John P A et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration *BMJ* 2009; 339 :b2700

142. Lipkus, I. M., Peters, E., Kimmick, G., Liotcheva, V., & Marcom, P. (2010). Breast Cancer Patients' Treatment Expectations after Exposure to the Decision Aid Program Adjuvant Online: The Influence of Numeracy. *Medical Decision Making*, *30*(4), 464–473.

143. Lipowski, Z. J. (1970). *Physical Illness, The Individual and the coping processes. The International Journal of Psychiatry in Medicine, 1(2), 91–102*

144. Little M, Paul K, Jordens C, Sayers E-J (2002) Survivorship and discourses of identity. Psycho-Oncology, 11;170-178

145. LoConte, N. K., Else-Quest, N. M., Eickhoff, J., Hyde, J., & Schiller, J. H. (2008). Assessment of guilt and shame in patients with non–small-cell lung cancer compared with patients with breast and prostate cancer. *Clinical lung cancer*, *9*(3), 171-178.

146. Lupton D (2012) Medicine as Culture: Illness, Disease and the Body. SAGE

147. Mackie, J. Ethics. London: Penguin, 1977.

148. MacNeill F and Irvine T (2021) Breast Surgery: GTIRFT Programme National Specialty Report

149. Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient education and counseling*, *60*(3), 301-312.

150. Manrique, O. J., Banuelos, J., Abu-Ghname, A., Nguyen, M. D., Tran, N. V., Martinez-Jorge, J., Harless, C., Sharaf, B., Jakub, J. W., Degnim, A. C., Boughey, J. C., & Jacobson, S. R. (2019). Surgical Outcomes of Prepectoral Versus Subpectoral Implant-based Breast Reconstruction in Young Women. *Plastic and reconstructive surgery. Global open*, *7*(3), e2119.

151. Martin, Emily (1990). *Toward an Anthropology of Immunology: The Body as Nation State. Medical Anthropology Quarterly, 4(4), 410–426.*

152. Masud, D., Sharp, O. L., Rosich-Medina, A., Köhler, G., & Haywood, R. M. (2021). Resuming autologous free tissue transfer for breast reconstruction in the COVID-19 era. *Journal of plastic, reconstructive & aesthetic surgery : JPRAS*, *74*(2), 407–447. https://doi.org/10.1016/j.bjps.2020.08.079

153. Mead N and Bower P (2000). Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med.* 51(7); 1087-1110

154. Mechanic D and Meyer S (2002) Concepts of trust among patients with serious illness. Social Science and Medicine. 51(5); 657 - 668

155. Mennie JC, Mohanna PN, O'Donaghue JM, Rainsbury R, Cromwell DA (2017). National trends in immediate and delayed post-mastectomy reconstruction procedures in England: A seven-year population cohort study. European Journal of Surgical Oncology. 43(1); 52-61

156. Merriam, S. B. (1998). Qualitative research and case study applications in education. San Francisco: Jossey-Bass.

157. Moher, D., Shamseer, L., Clarke, M. *et al.* Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev* **4,** 1 (2015). https://doi.org/10.1186/2046-4053-4-1

158. Mulley A, Trimble C, Elwyn G (2012) Patients' Preferences Matter: Stop the silent misdiagnosis. The King's Fund

159. Munthe-Kaas, H., Bohren, M.A., Glenton, C. *et al.* Applying GRADE-CERQual to qualitative evidence synthesis findings—paper 3: how to assess methodological limitations. *Implementation Sci* **13,** 9 (2018). https://doi.org/10.1186/s13012-017-0690-9

160. Munthe-Kaas, H., Nøkleby, H., Lewin, S. *et al.* The TRANSFER Approach for assessing the transferability of systematic review findings. *BMC Med Res Methodol* **20,** 11 (2020). https://doi.org/10.1186/s12874-019-0834-5

161. Nelson JA, Nelson P, Tchou J, Serletti J, Wu L (2011) The ethnic divide in breast reconstruction: A review of the current literature and directions for future research. Cancer Treatment Reviews. 38; 362-367

162. Nack, Adina (2002). “Bad Girls and Fallen Women: Chronic Std Diagnoses as Gateways to Tribal Stigma.” Symbolic Interaction 25:463–85.

163. National Cancer Institute. (2017) *Breast Cancer After Mastectomy* (https://www.cancer.gov/types/breast/reconstruction-fact-sheet)

164. National Institute for Health and Care Excellence. Early and locally advanced breast cancer: diagnosis and management. NICE guideline [NG101], July 2018

165. National Health Service. PIP Breast Implants (2019). https://www.nhs.uk/conditions/pip-implants/; accessed 18/01/2021.

166. Neuburger J, MacNeill F, Jeevan R*, et al* Trends in the use of bilateral mastectomy in England from 2002 to 2011: retrospective analysis of hospital episode statistics *BMJ Open* 2013;**3:**e003179. doi: 10.1136/bmjopen-2013-003179

167. Neuman, M.D. and Bosk, C.L. (2012), What We Talk about When We Talk about Risk: Refining Surgery's Hazards in Medical Thought. The Milbank Quarterly, 90: 135-159.

168. Noblit, G. W., Hare, R. D., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). sage.

169. Novick, Gina. Is there a bias against telephone interviews in qualitative research? Research in Nursing & Health, 2008, 31, 391-398.

170. Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*. https://doi.org/10.1177/1609406917733847

171. Noyes J, Booth A, Cargo M, Flemming K, Harden A, Harris J, Garside R, Hannes K, Pantoja T, Thomas J. Chapter 21: Qualitative evidence. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). *Cochrane Handbook for Systematic Reviews of Interventions* version 6.1 (updated September 2020). Cochrane, 2020.

172. Noyes, J., Booth, A., Lewin, S. *et al.* Applying GRADE-CERQual to qualitative evidence synthesis findings–paper 6: how to assess relevance of the data. *Implementation Sci* **13,** 4 (2018). https://doi.org/10.1186/s13012-017-0693-6

173. Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed

Method Implementation Research. *Administration and policy in mental health*, *42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

174. Palley, Howard A. "THE EVOLUTION OF FDA POLICY ON SILICONE BREAST IMPLANTS: A CASE STUDY OF POLITICS, BUREAUCRACY, AND BUSINESS IN THE PROCESS OF DECISION-MAKING." *International Journal of Health Services* 25, no. 4 (1995): 573-91. Accessed January 18, 2021. http://www.jstor.org/stable/45131712.

175. Patel-Kerai G, Harcourt D, Rumsey N, Naqvi H, White P (2017) The psychosocial experiences of breast cancer amongst Black, South Asian and White survivors: do differences exist between ethnic groups? 26; 515-522

176. Patton MQ (1990) Qualitative Evaluation and Research Methods. 2nd edition. Sage, Newbury Park, California

177. Pellisé, F., Vila-Casademunt, A., Núñez-Pereira, S. *et al.* Surgeons' risk perception in ASD surgery: The value of objective risk assessment on decision making and patient counselling. *Eur Spine J* (2022). https://doi.org/10.1007/s00586-022-07166-2

178. Peters, E. (2012). Beyond comprehension: The role of numeracy in judgments and decisions. *Current Directions in Psychological Science*, *21*(1), 31-35.

179. Peters, E., Hart, P. S., & Fraenkel, L. (2011). Informing patients: the influence of numeracy, framing, and format of side effect information on risk perceptions. *Medical Decision Making*, *31*(3), 432-436.

180. Ponterotto, J. G. (2006). Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. *The qualitative report*, *11*(3), 538-549.

181. Pope Catherine, Mays Nick. Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research *BMJ* 1995; 311 :42

182. Potter S, Conroy EJ, Cutress RI, *et al.* Short-term safety outcomes of mastectomy and immediate implant-based breast reconstruction with and without mesh (iBRA): a multicentre, prospective cohort study. Lancet Oncol, 20 (2019), pp. 254-266

183. Potter S, Mills N, Cawthorn S, Wilson S, Blazeby J. Exploring inequalities in access to care and provision of choice to women seeking breast reconstruction surgery: a qualitative study. British Journal of Cancer. 2013; 109; 1181-1191

184. Potter S, Mills N, Cawthorn S, Wilson S, Blazeby J. Exploring information provision in reconstructive breast surgery: A qualitative study. The Breast. 2015; 24; 732-738

185. Purcell C, Hilton S, McDaid L (2014) The stigmatisation of abortion: a qualitative analysis of print media in Great Britain in 2010, Culture, Health & Sexuality, 16:9, 1141-1155, DOI: 10.1080/13691058.2014.937463

186. Pusic, Andrea L.; Klassen, Anne F.; Scott, Amie M.; Klok, Jennifer A.; Cordeiro, Peter G.; Cano, Stefan J. (2009). *Development of a New Patient-Reported Outcome Measure for Breast Surgery: The BREAST-Q. Plastic and Reconstructive Surgery, 124(2), 345–353.* doi:10.1097/PRS.0b013e3181aee807

187. Quaresma M, Coleman MP, Rachet B. 40-year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971-2011: a population-based study. Lancet. 2015 Mar 28;385(9974):1206-18. doi: 10.1016/S0140-6736(14)61396-9. Epub 2014 Dec 3. Erratum in: Lancet. 2015 Mar 28;385(9974):1182. PMID: 25479696.

188. Rainsbury D and Willett A. Oncoplastic Breast Reconstruction: Guidelines for Breast Practice. ABS and BAPRAS. 2012.

189. Reaby LL. 1998a. Breast restoration decision-making: enhancing the process. Cancer Nursing. 21(3): 196-204

190. Reaby LL. 1998. Reasons why women who have mastectomy decide to have or not to have breast reconstruction. Plastic and Reconstructive Surgery. 101:1810-8

191. Retrouvey H, Zhong T, Gagliardi A, Baxter N, Webster F (2019) How patient acceptability affects access to breast reconstruction: a qualitative study. BMJ Open. 9;e029048

192. Richards H and Emslie C (2000) The ‘doctor’ or the ‘girl from the University’? Considering the influence of professional roles on qualitative interviewing. Family Practice. 17(1); 71-75

193. Robinson, J. O. (1986). *Treatment of breast cancer through the ages. The American Journal of Surgery, 151(3), 317–333.* doi:10.1016/0002-9610(86)90461-7

194. Rottmann N, Helmes A, Vogel B (2010) Patients’ Needs and Experiences at Breast Cancer Diagnosis: How Perceived Threat Influences the Physician-Patient Interaction.

Journal of Psychosocial Oncology, 28:2, 157-172

195. Rubin L, Chavez J, Alderman A, Pusic AL. ‘Use what God has given me’: Difference and disparity in breast reconstruction. Psychology and Health. 2013; 28:10, 1099-1120

196. Rubin L, Fitts M, Becker A. ‘Whatever feels good in my soul’ Body Ethics and Aesthetics Among African American and Latina Women. Culture, Medicine and Psychiatry. 2003. 27; 49-75

197. Rubin, L. R., & Tanenbaum, M. (2011). “Does That Make Me A Woman?”: Breast Cancer, Mastectomy, and Breast Reconstruction Decisions Among Sexual Minority Women. Psychology of Women Quarterly, 35(3), 401–414.

198. Sacks, G. D., Dawes, A. J., Ettner, S. L., Brook, R. H., Fox, C. R., Maggard-Gibbons, M., ... & Russell, M. M. (2016). Surgeon perception of risk and benefit in the decision to operate. *Annals of surgery*, *264*(6), 896-903.

199. Sajid MS, Betal D, Akhter N, Rapisarda IF, Bonomi R. Prevention of post-operative seroma-related morbidity by quilting of latissimus dorsi flap donor site: A systematic review. Clinical Breast Cancer 2011. 11(6): 357-363

200. Sandelowski M (1995) Sample Size in Qualitative Research. Research in Nursing and Health. 18. 179-183

201. Sandham and Harcourt (2007) Partner experiences of breast reconstruction post mastectomy. European Journal of Oncology Nursing. 11; 66-73

202. Saxena P. Trading and Managing Stigma: Women’s Accounts of Breast Implant Surgery. Journal of Contemporary Ethnography. 2013; 42(3); 347-377

203. Schwandt, T. A., Lincoln, Y. S., & Guba, E. G. (2007). Judging interpretations: But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New directions for evaluation*, *114*, 11-25.

204. Serletti J (2006) Breast Reconstruction with the TRAM Flap: Pedicled and Free. Journal of Surgical Oncology. 94: 532-537

205. Sheehan, A., Gribble, K. & Schmied, V. It’s okay to breastfeed in public but…. *Int Breastfeed J* **14,** 24 (2019). https://doi.org/10.1186/s13006-019-0216-y

206. Slovic, P., Fischhoff, B., & Lichtenstein, S. (1980). Facts and fears: Understanding perceived risk. In *Societal risk assessment* (pp. 181-216). Springer, Boston, MA.

207. Slovic, P., & Peters, E. (2006). Risk perception and affect. *Current directions in psychological science*, *15*(6), 322-325.

208. SNYDERMAN, REUVEN K. M.D.; GUTHRIE, RANDOLPH H. M.D. RECONSTRUCTION OF THE FEMALE BREAST FOLLOWING RADICAL MASTECTOMY, Plastic and Reconstructive Surgery: June 1971 - Volume 47 - Issue 6 - p 565-567

209. Somogyi R, Webb A, Baghdikian N, Stephenson J, Edward K-L, Morrison W (2015) Understanding factors that influence breast reconstruction decision making in Australian women. The Breast. 24(2); 124-130

210. Somogyi R, Ziolkowski N, Osman F, Ginty A, Brown M. (2018) Breast Reconstruction: Updated overview for primary care physicians. Canadian Family Physician. 64; 424-432

211. Sontag S. (1979) *Illness as Metaphor*. Penguin Classics.

212. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews 2017, Issue 4. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub5. Accessed 17 August 2021.

213. Stewart M., Brown J.B., Donner A., McWhinney I.R., Oates J., Weston W. & Jordan J. (2000) The impact of patient-centered care on outcomes. *The Journal of Family Practice***49**(9), 796–804.

214. Stewart M, Brown JB, Weston WW, McWhinney IR (1995) *Patient-Centred Medicine: Transforming the Clinical Method*. Sage, Thousand Oaks

215. Strauss, A. & Corbin, J. 1998. Basics of Qualitative Research. Thousand Oaks, CA: Sage Publications.

216. Suri H. Purposeful sampling in qualitative research synthesis. *Qualitative Research Journal* 2011; **11**: 63-75.

217. Thomas J and Harden A (2008) Methods for thematic synthesis of qualitative research in systematic reviews; BMC Medical Research Methodology. 8; 45

218. Thompson AJ, Topping AE, Jones LL 'Surely you're not still breastfeeding': a qualitative exploration of women's experiences of breastfeeding beyond infancy in the UK *BMJ Open* 2020;**10:**e035199. doi: 10.1136/bmjopen-2019-035199

219. Thorne S. Data analysis in qualitative research. *Evidence-Based Nursing* 2000;**3:**68-70.

220. Thorne S, Jensen L, Kearney MH, Noblit G, Sandelowski M. Qualitative Metasynthesis: Reflections on Methodological Orientation and Ideological Agenda. *Qualitative Health Research*. 2004;14(10):1342-1365.

221. Tollow P, Williams V, Harcourt D, Paraskeva N (2019) "It felt like unfinished business, it feels like that's finished now": Women's experiences of decision making around contralateral prophylactic mastectomy. Psycho-oncology; 28; 1328 - 1334

222. Tong, A., Flemming, K., McInnes, E. *et al.* Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* **12,** 181 (2012). https://doi.org/10.1186/1471-2288-12-181

223. Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 19(6); 349-357

224. Uroskie, T. W., & Colen, L. B. (2004). *History of Breast Reconstruction. Seminars in Plastic Surgery, 18(2), 65–69.* doi:10.1055/s-2004-829040

225. Vasileiou, K., Barnett, J., Thorpe, S. *et al.* Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol* **18,** 148 (2018).

226. Wakefield, A. J., Murch, S. H., Anthony, A., Linnell, J., Casson, D. M., Malik, M., ... & Walker-Smith, J. A. (1998). RETRACTED: Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children.

227. Wazir U, Kasem A, Mokbel K. The clinical implications of poly implant prothèse breast implants: an overview. Arch Plast Surg. 2015 Jan;42(1):4-10. doi: 10.5999/aps.2015.42.1.4. Epub 2015 Jan 14. PMID: 25606483; PMCID: PMC4297804.

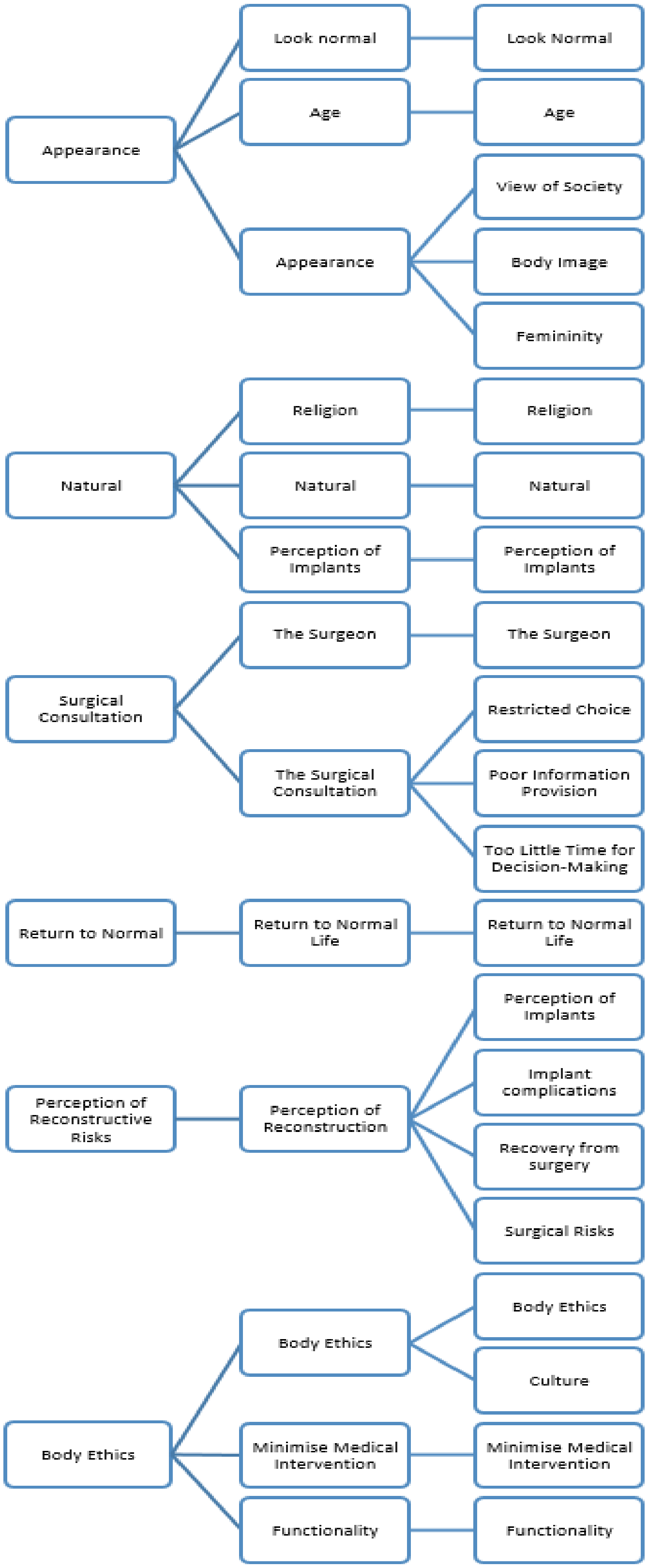
228. Weber, Max. 2001 (1930). *The Protestant Ethic and the Spirit of Capitalism*. New York, NY: Routledge.

229. Williams Camus JT. Metaphors of cancer in scientific popularization articles in the British press. *Discourse Studies*. 2009;11(4):465-495. doi:10.1177/1461445609105220

230. Wilson, T. D., & Brekke, N. (1994). Mental contamination and mental correction: unwanted influences on judgments and evaluations. *Psychological bulletin*, *116*(1), 117.

231. Wignarajah, P., Forouhi, P., & Malata, C. M. (2020). The past, the present and the future of UK breast reconstruction—are our practices outdated in 2020?. *Gland Surgery*, *9*(4), 1076.

APPENDIX 1 – Thematic Synthesis Coding Hierarchy



APPENDIX 2 – Patient Interview Schedule

PATIENT INTERVIEW SCHEDULE

Introductory Statement:

“Hello [patient’s name], my name is Dinush Lankage, I’m a doctor and researcher from the University of Birmingham. As you will remember from our previous conversation, we are speaking today to discuss your experience of choosing a type of breast reconstruction, with a focus on factors you found important in your choice. How would you like to be addressed during this interview? I would like to confirm once again that you are still happy to go along with this interview, and that you are also happy for this discussion to be recorded. In the unlikely situation that you are caused emotional or psychological distress, you have already been given the name and contact details of a breast care nurse. Should you not wish to answer a question, that is not a problem, and you will not have to provide a reason for this. You may end the interview at any time, should you wish. If you feel distressed outside the normal working hours of your breast care nurse, I want to make you aware of 24 hours services, such as the Samaritans helpline, or if your distress is quite severe, the NHS 111 or 999 services. This research will guide the development of the NHS breast reconstruction service to support the decision making of future patients. Thank you for your participation, and remember that we are exploring your views – there are no wrong answers.”

NB. The lettered questions following the numbered questions are prompts only; as such they will only be asked explicitly if these questions are not answered by the patient after sufficient time is given to answer the main (numbered) question.

1. Can you tell me about your experience leading up to your breast reconstructive surgery?
    a. How were you diagnosed (with a condition requiring mastectomy)?
    b. How were you treated?
    c. Why did you choose to have breast reconstruction as opposed to no reconstruction?
    d. Why was it important to you to have a breast reconstruction operation?
    e. Any effect on choice in type of breast reconstruction?
    f. Effect on timing of reconstruction?
2. Can you tell me what you remember about making a choice in type of breast reconstruction?

    Follow up question in case patient finds this too broad: Could you tell me what happened when you were offered a breast reconstruction operation?
    a. What types of breast reconstruction were you offered?
    b. Which types did you consider?
    c. Which did you choose? How easy or difficult was it to make the choice?
    d. How do you feel about this choice now?
3. Do you remember what was important to you at the time of making a choice?
    a. Procedural? [Recovery time, complications, further procedures, length of procedure]
    b. Cosmetic? [Scars, breast size, abdominoplasty],
    c. View of self? [Confidence, body image, normality, prosthesis]
    d. Perception of others? Partner?

    e. Religion, culture?
    f. Personal responsibilities? [Work, finance, dependents, carer, relationship status]
    g. Why did you not choose the other two types of reconstruction?
    h. If you could name one factor most influential in your choice, what would it be? Would you be able to rank any other influencing factors, in order of importance?
4. Can you tell me how you went about making your decision?
    a. Did any aspects of the NHS healthcare service impact your choice? Any adverse impact to your choice?
    b. Surgeon's consultation? Nurse's consultation?
    c. Did distance/travel to breast reconstructive services affect your choice?
    d. Did you feel as if you had a prolonged waiting time to be seen for a breast reconstruction consult?
    e. What do you remember of the first time breast reconstruction was discussed with you?
    f. What were your main sources of information? [Read, watched, or spoke to]
    g. Was there a particular choice you had in mind prior to meeting for a breast reconstruction consultation?
    h. Improvements? Including ways NHS breast reconstruction services can be improved so that decision making can be better supported?
5. If your close friend or family member were considering a breast reconstruction operation, what would you tell them?

a. How satisfied were you the outcome of your breast reconstruction procedure?
b. How would you describe the procedures available to a close friend or family member?
c. What outcome were you expecting?
d. If you could go back in time, and were offered a breast reconstructive operation again, would you make the same choice? Why/why not?

“Thank you for your time, do you have any questions?”

APPENDIX 3 – Clinician Interview Schedule

CLINICIAN INTERVIEW SCHEDULE

Introductory Statement:
“Hello, my name is Dinush Lankage, I’m a doctor and researcher from the University of Birmingham. As you will remember from my email, we are speaking today to discuss your view regarding the breast reconstruction service, with a focus on factors you believe are influential to patients when choosing a type of breast reconstruction. I would like to confirm once again that you are still happy to be interviewed, and that you are also happy for this discussion to be recorded. Should you not wish to answer a question, that is not a problem, and you will not have to provide a reason for this. The interview can end at any time, should you wish. Thank you for your participation.”

NB. The lettered questions following the numbered questions are prompts only; as such they will only be asked explicitly if these questions are not answered by the clinician/breast care nurse after sufficient time is given to answer the main (numbered) question.

1. Can you tell me about your breast reconstruction service?
    a. If you do not offer a breast reconstruction service personally, can you tell me about the breast reconstruction service to which you refer your patients?
    b. What types of reconstructive procedures are offered?
    c. How often are different procedures performed (approximately)? Do you think there is a preference for a type of reconstruction? [patient choice, access to other services, procedures offered]
2. What do you say to patients when you discuss breast reconstruction?
    a. How would you describe your style of information provision?

   b. What are the most important details you give to patients to assist them in decision making? What information do you give that is most influential of what the patient chooses?

   c. Do you offer any support services for patient decision making? What do you think of these services? [Leaflet, expert patients, support groups, breast care nurses]

   d. How do you think patients feel about the discussion afterwards?

   e. What support do you feel patients require when choosing a type of breast reconstruction?

   f. Are you the first person to introduce the option of breast reconstruction to patients?

   g. How well informed about breast reconstruction do you think your patients are, prior to coming to see you?

   h. What do you do when you find a patient making a wrong decision?

   i. Could you describe the last couple of breast reconstruction discussions you've had?

   j. What do you think is the best method of breast reconstruction? The worst method?

3. What factors do you think are influential in patient choice in type of breast reconstruction?

   a. Procedural? [Recovery time, complications, further procedures, length of procedure]

   b. Cosmetic? [Scars, breast size, abdominoplasty]

   c. View of self? [Confidence, body image, normality, prosthesis]

   d. Perception of others? Partner?

   e. Religion, culture?

   f. Personal responsibilities? [Work, finance, dependents, carer, relationship status]

    g. Emotional or psychological burden of breast cancer diagnosis/living with breast cancer?
    h. Does radiotherapy influence your choice in type of reconstruction, or reconstructive timing? How?
    i. If you could name one factor most influential in patient choice, what would it be?
    j. Why do you think patients choose to have breast reconstruction (as opposed to no reconstruction)?

4. What do you think of patient expectations of breast reconstruction surgery?
    a. What do you make of patient satisfaction with the breast reconstructive service offered?
    b. How could your service better support patient decision making? If you could make one improvement to better support patient decision making in the service, what would it be?
    c. How could your service improve patient satisfaction?
    d. Do you think there is a patient group who could have been better supported in their decision making?