Guideline for the role of practitioner psychologists in the assessment and support of women considering risk-reducing breast surgery
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Tel: 0116 252 9523; E-mail: P4P@bps.org.uk.
Contents

Working group leads and main authors .........................................................................................3
Working group contributors and authors .........................................................................................3
Acknowledgments ..........................................................................................................................4
1. Scope of the guidelines .............................................................................................................5
2. Background to these guidelines ...............................................................................................6
3. Motivation for risk-reducing breast surgery ............................................................................8
   3.1 Family history .....................................................................................................................8
   3.2 Personal history ..................................................................................................................8
      3.2.1 Personal history: previous breast cancer .................................................................8
      3.2.2 Personal history: current (recently diagnosed) breast cancer ..............................8
      3.2.3 Personal history: increased risk due to treatment for another type of cancer ....9
   3.3 People without family or personal history .......................................................................9
   3.4 Definitions for clinical risk of breast cancer .....................................................................9
      3.4.1 ‘High risk’ ..................................................................................................................9
      3.4.2 ‘Moderate risk’ ..........................................................................................................9
      3.4.3 ‘Near population risk’ ............................................................................................10
   3.5 Complex requests for risk-reducing breast surgery .......................................................10
      3.5.1 Perception of risk .....................................................................................................10
      3.5.2 Psychological factors ...............................................................................................10
      3.5.3 The role of the multidisciplinary team where decisions are complex ...............12
      3.5.4 Complex decision-making and immediate contralateral surgery ....................12
4. The role of psychologists as part of the patient’s decision-making process ......................14
   4.1 Guidance recommendations .............................................................................................14
   4.2 Psychological theory .........................................................................................................15
      4.2.1 Decision-making theory .........................................................................................15
      4.2.2 Decision aids ............................................................................................................16
   4.3 When should a psychologist be involved? ......................................................................16
   4.4 Training and Qualifications .............................................................................................17
5. The psychology consultation .....................................................................................................18
   5.1 Referral process ...............................................................................................................18
5.1.1 In cases where women are requesting an urgent contralateral mastectomy...... 18
5.2 Recommendations for how the surgical team can introduce the aims of the psychological consultation .................................................................................................................. 18
5.2.1 What if a woman declines a psychology appointment? ........................................ 19
5.2.2 What information does a psychologist need in order to support a woman with her decision-making? ........................................................................................................ 19
5.3 Who is invited to the consultation? ......................................................................... 19
5.4 Format of the psychology consultation .................................................................... 20
5.5 Self-report measures .............................................................................................. 21
5.6 Possible outcomes of the psychological consultation .............................................. 22
5.7 The psychology report .......................................................................................... 22
5.8 Follow-up .............................................................................................................. 23
6. Broader support and resources .................................................................................. 24
7. Service evaluation: Demonstrating quality and outcomes ........................................ 25
8. Recommendations for future research ...................................................................... 26
9. References ............................................................................................................... 27
10. Appendices ............................................................................................................ 33
Working group leads and main authors

**Dr Olivia Donnelly**, Macmillan Consultant Clinical Psychologist, Clinical Health Psychology, North Bristol NHS Trust.

**Dr Marilyn Owens**, Macmillan Consultant Clinical Psychologist, Specialist Psychological Services in Cancer and Palliative Care, South Staffordshire and Shropshire Healthcare NHS Foundation Trust.

Working group contributors and authors

**Dr Jan Ablett**, Macmillan Consultant Clinical Psychologist, Clinical Health Psychology Service-Cancer, Royal Liverpool University Hospital.

**Dr Helen Beesley**, Honorary Research Fellow – University of Liverpool.

**Dr Peter Blackburn**, Consultant Clinical Psychologist, Dept. of Clinical Health Psychology, Gateshead Health NHS Foundation Trust.

**Dr Mary Burgess**, Lead Consultant Clinical Psychologist, General Oncology Psychological Care Team, University College London Hospitals NHS Foundation Trust.

**Lois Coy**, Assistant Psychologist, North Bristol NHS Trust.

**Dr Louise Fairburn**, Macmillan Principal Clinical Psychologist Liverpool Cancer Psychology Service, Royal Liverpool and Broadgreen University Hospital NHS Trust.

**Dr Rachel Foxwell**, Clinical Psychologist, Oncology Health Centre, Hull and East Yorkshire Hospitals NHS Trust.

**Dr Ailyn Garley**, Principal Clinical Psychologist, East Lancashire Hospitals NHS Trust.

**Dr Penny Hopwood**, Lead Consultant in Psycho-Oncology, Christie Hospital Foundation Trust; Honorary Professor of Psycho-Oncology, Salford University (2008–2015).

**Bethan Jones**, Assistant Psychologist, North Bristol NHS Trust.

**Dr Emma Lewis**, Lead Clinical Psychologist, Oncology Health Centre, Hull and East Yorkshire Hospitals NHS Trust.

**Dr Joanna Levene**, Lead Clinical Psychologist for Cancer and Palliative Care, Nottinghamshire Healthcare NHS Foundation Trust.

**Dr Joy MacInness**, Lead Clinical Psychologist for Surgical Pathways, Royal Free London NHS Foundation Trust.

**Dr Lottie Morris**, Clinical Psychologist, Hospice Isle of Man.

**Dr Lesley Scott**, Macmillan Senior Clinical Psychologist, Clinical Health Psychology Service-Cancer, Royal Liverpool University Hospital.

**Dr Julie Wisely**, Consultant Clinical Psychologist, Greater Manchester Mental Health NHS Foundation Trust.
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1. Scope of the guidelines

The guidelines have been developed by a working group of the British Psychological Society’s Division of Clinical Psychology Faculty for Oncology and Palliative Care.

The guidance is aimed at HCPC registered practitioner psychologists1 who work within Breast Care and Plastic and Reconstructive Surgery teams (or receive referrals from such teams) where patients may be considered for risk-reducing breast surgery.

There are presently no established guidelines to aid psychologists in this role and this document aims to provide useful information and recommendations to facilitate their work as part of multidisciplinary teams. It is hoped that the guidance will contribute to clear pathways regarding psychological consultation and support for adult women who may be considered for risk-reducing breast surgery. It is recommended that this guidance also informs surgical pathways and local commissioning arrangements in relation to psychological assessment and support within this specialist area.

Of note, the focus of this guidance is the role of the psychologist within the pathway for women considering risk-reducing breast surgery. The guidance does not take a position on whether a woman is or is not medically suitable for surgery and does not see this as the remit or role of psychologists. Medical suitability is fundamentally a decision for surgeons, medical oncologists and genetic counsellors within multidisciplinary teams, within specialist units based on national guidance (e.g. Royal College of Surgeons) and local commissioning arrangements regarding provision for the procedure. We recommend referring to the Manchester documents for broader information and recommendations regarding multidisciplinary approaches to bilateral and contralateral risk-reducing surgery pathways (Basu et al., 2015; Laloo et al., 2000).

In exceptional circumstances the multidisciplinary team may make a decision that surgical removal of healthy breast tissue is supported for women who have been treated for breast cancer and are not considered to be at heightened risk of developing a further primary breast cancer. This guidance recommends these procedures are discussed as elective procedures. While the main scope of this guidance is to consider the role of psychologists with women considering risk-reducing breast surgery (sometimes referred to as prophylactic mastectomy), it acknowledges the complexity of decision-making for women who have had a primary breast cancer and who are considering further elective surgery (e.g. for reasons of symmetrisation). In these circumstances, this guidance may facilitate psychologists in supporting complex decision-making alongside the multidisciplinary team (e.g. in relation to body image; cancer-related anxiety).

These guidelines primarily concern adult women but could guide an individualised assessment in the rare event that a man is medically suitable for risk-reducing breast surgery. Furthermore, these guidelines do not attempt to address the specialist needs of women with specific learning or communication needs; or the needs of young people. In these cases the psychologist is advised to consider this document alongside relevant policy guidance and clinical experience regarding the assessment and support of these individuals.

1 Furthermore referred to as psychologists
2. Background to these guidelines

Risk-reducing breast surgery is one of a range of treatment options available to women who are concerned about their risk of developing a primary breast cancer. Surgical options under consideration include contralateral or bilateral mastectomy alone or mastectomy and either immediate or delayed reconstruction. Surgery has been shown to significantly reduce incidence of breast cancer and increase life expectancy rates for those with a high risk of breast cancer (e.g. Schrag et al., 1997). Other options for women with a high risk of breast cancer include close surveillance (using screening procedures, e.g. ultrasound, mammogram and MRI) and/or risk-reducing medications (‘chemoprevention’).

Rates of requests for risk-reducing surgery have increased significantly in recent years. For example, the Surveillance, Epidemiology, and End Results Program (SEER) data from the US has confirmed a 150 per cent increase in rates of contralateral risk-reducing mastectomy over the last decade, despite rates of contralateral breast cancer decreasing due to effective endocrine therapies (Tuttle et al., 2007; Nichols et al., 2011).

A number of advances have resulted in the exponential rise in the frequency of risk-reducing mastectomy:

Firstly, recent developments in gene testing and cancer epidemiological models have allowed physicians and surgeons to better estimate some individuals’ risks of developing breast cancer. There is good evidence that risk-reducing mastectomy reduces (though doesn’t eliminate) the occurrence of a new breast cancer and conveys a clear survival advantage in cases where there is a significant risk (Metcalfe et al., 2014; Evans et al., 2013). Research indicates it conveys little survival advantage for people with no known genetic mutation (Lostumbo, Carbine & Wallace, 2010), although requests from individuals of all risk levels have increased over recent years.

Secondly, recent advances in surgical techniques of both mastectomy and reconstruction have resulted in more reliable and acceptable outcomes, especially with regards to cosmesis.

Thirdly, there has also been a marked increase in requests for risk-reducing surgery following high profile celebrity endorsement, notably Angelina Jolie (e.g. Evans et al., 2015) including from those at lower risk groups. This for those where the procedure is not medically indicated raises the issue of patient choice in this area. The Department of Health (2010) paper Equity and Excellence: Liberating the NHS places patient’s needs, wishes and preferences at the heart of clinical decision-making with the premise ‘no decision about me, without me’ (p.3, see also Coulter & Collins, 2011). It highlights the importance of providing accurate and accessible information in order for people to make informed decisions about their care. However, the availability of risk-reducing surgery is often limited in many NHS trusts based on local commissioning arrangements.

The decision to pursue risk-reducing surgery is complex, personal and irreversible. As recently highlighted, ‘risk-reducing procedures are often invasive and carry iatrogenic risk’ (Fielden et al., 2017, p.1), including risk of infection, impact on sexuality (Arver et al., 2011), long-term pain and numbness, and distress associated with body image (Brandberg
et al., 2008; Bresser et al., 2006; Frost et al., 2005; Gahm et al., 2010; Geiger et al., 2006; Van Oostrom et al., 2003).

Although risk-reducing surgery increases life expectancy for those with a high risk (e.g. those with a BRCA gene mutation) it has not been shown to do so for those affected by breast cancer with a lower risk (Rebbeck et al., 2004). It is therefore important that women considering this surgery are able to weigh up the benefits and risks of surgical options and alternatives as part of coming to an informed decision. NICE guidance (2013) suggests that the process of decision-making should include the input and support from a multidisciplinary team, including access to psychological assessment and counselling. This guidance provides further information to support the psychologist within this specialist role.
3. Motivation for risk-reducing breast surgery

This guideline clarifies the patient pathway for women seeking risk-reducing mastectomy (RRM) in the following groups:

3.1 Family history
Those with a family history (including but not exclusive to those with genetic risk markers e.g. BRCA1, BRCA2, TP53) who may have high or moderate risk of developing breast cancer, requesting bilateral surgery.

3.2 Personal history
Increasing numbers of women who have a personal history of breast cancer in one breast are requesting risk-reducing mastectomy of their contralateral breast. Patients in the personal history group can be subdivided into two groups according to the stage of treatment of their breast cancer.

3.2.1 Personal history: previous breast cancer
These patients have already had a wide local excision (lumpectomy) or mastectomy for cancer in one breast (with or without reconstruction) and are now requesting a contralateral mastectomy or bilateral mastectomy, with or without reconstruction. Their primary motivation for this may include:

- Concerns about their risk of developing cancer in the contralateral breast. Of note, contralateral mastectomy is effective in reducing risk of a primary breast cancer and not a recommended treatment for reducing risk of distal (secondary) recurrence. This may need clarifying for patients who may understandably, but mistakenly, believe that risk-reducing surgery reduces risk of secondary recurrence, especially where this is their primary motivating factor for surgery.

- Concerns regarding symmetry as a consequence of therapeutic surgery. Beesley, Holcombe, Brown & Salmon (2013) caution against using the routine use of the term ‘risk-reducing’ in these cases as the rationale for surgery is not for reduction in clinical risk of breast cancer; instead, we recommend these are instead discussed as elective mastectomy procedures.

3.2.2 Personal history: current (recently diagnosed) breast cancer
This is a relatively small group of patients, diagnosed with breast cancer, that are awaiting treatment and request contralateral risk-reducing mastectomy at the time of initial surgery to treat the cancer. These patients may also have the option of bilateral immediate reconstruction.

Due to the necessary time limit in operating on their breast cancer, there is an urgency to evaluate and assess the suitability for a risk-reducing mastectomy alongside a therapeutic mastectomy\(^2\). It is just as important in these situations to calculate the likely clinical risk (of a new cancer) and to discuss this with the women and to give them opportunities to make informed decisions about their surgeries. The complex assessment and support needs of this group of women will be considered in greater detail in 3.5.4.

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\(^2\) Therapeutic mastectomy – the surgical term for a mastectomy that is performed with the aim of treating a breast cancer.
3.2.3 Personal history: increased risk due to treatment for another type of cancer
This may include individuals who have had chest radiation for Hodgkin’s and non-Hodgkin’s lymphoma in childhood, who are estimated to have a 20 times higher risk of breast cancer (Moskowitz et al., 2014).

3.3 People without family or personal history
Other individuals who would not fulfil the remit for risk-reducing surgery but may request elective breast mastectomy for other reasons, including health-related anxiety, difficulties with self-examination/surveillance, to improve cosmesis, or with the aim of alleviating breast pain.

Surgery may be an option for women in some cases but, as mentioned earlier, we recommend these procedures are discussed as ‘elective’ surgeries. Although there is some guidance in 3.5 ‘complex requests for contralateral breast surgery’ these guidelines focus on the role of the psychologist in supporting women considering risk-reducing surgery.

3.4 Definitions for clinical risk of breast cancer
NICE guidance CG164 (2013) distinguishes between three risk groups which are associated with different recommended management:

<table>
<thead>
<tr>
<th>Risk Group</th>
<th>10 year Risk</th>
<th>Lifetime Risk from age 20</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Near population risk</td>
<td>&lt; 3%</td>
<td>&lt; 17%</td>
<td>Primary care</td>
</tr>
<tr>
<td>Moderate risk</td>
<td>3–8%</td>
<td>17–30%</td>
<td>Secondary care or tertiary care if requesting risk-reducing mastectomy</td>
</tr>
<tr>
<td>High risk</td>
<td>&gt; 8%</td>
<td>&gt; 30%</td>
<td>Tertiary care (Genetics Service)</td>
</tr>
</tbody>
</table>

3.4.1 'High risk'
Patients are at a high risk of developing breast cancer by virtue of their family history, pre-existing breast changes or positive genetic screening (BRCA 1 or 2). NICE recommends that clinical teams discuss the benefits of risk-reducing mastectomy with women in this group. There is good evidence to support the use of risk-reducing mastectomy in women at high risk of developing breast cancer (Hartmann et al., 1999) with studies showing that bilateral prophylactic mastectomy reduces the risk of breast cancer in women with BRCA1/2 mutations by approximately 90 per cent (Rebbeck et al., 2004).

3.4.2 'Moderate risk'
Patients are at a moderate risk of developing breast cancer by virtue of their family history and/or pre-existing breast changes. These patients may consider undergoing a risk-reducing mastectomy.
3.4.3 'Near population risk'

The procedure is not recommended from a risk-reduction perspective for women within this group.

Of note, the labels ‘high’, ‘medium’ and ‘near population’ risk should be used with caution, as perceptions of what these mean in real terms may vary significantly (e.g. someone may see being advised they are at a high risk of breast cancer as a ‘fait accompli’ that they will get cancer, and yet have a 70 per cent chance of not developing breast cancer. Instead, we recommend that patients are given figures based on 10 year risk and lifetime risk. Similarly, it’s not uncommon for people to be advised that surgery will reduce their risk by 90 per cent, but the degree of risk reduction (and whether this seems beneficial from a patient’s perspective vis-à-vis possible complications) will vary depending on whether someone has a 12 per cent vs 85 per cent life time risk.

3.5 Complex requests for risk-reducing breast surgery

Women who have a personal history of breast cancer often have complex, multifactorial reasons for requesting contralateral breast surgery.

3.5.1 Perception of risk

Although clinicians may expect that individuals base their decisions primarily on objective or probabilistic risk ‘women’s categorical perceptions of risk may not closely correspond to objective risk’ (Fielden et al., 2017, p.7) and decisions are influenced by a broader array of factors. For example, Pachur et al. (2012) highlight that people often use heuristics (‘rules of thumb’) to make decisions based on guides other than risk, including relying on their emotions rather than on objective risk and rely on verbal labels (e.g. ‘high’) rather than specific figures.

3.5.2 Psychological factors

Women who have experienced breast cancer may have specific fears around recurrence, the side effects of chemotherapy, as well as for their family’s future.

Studies have shown that those with high levels of cancer worry commonly overestimate their risk for developing contralateral breast cancer, and are less inclined to fully consider the risks and benefits, meaning that worry ‘hijacked’ decision-making (Fielden et al., 2017, p.7). Individuals may confuse the role of surgery as being to reduce risk of secondary recurrence rather than to reduce the risk of a further primary breast cancer, something that psychologists new to the area also often confuse. Individuals may also overestimate the risk-reducing benefits of surgery (e.g. re: increasing life expectancy in those who are not in the medically high risk group), while underestimating the potential adverse impacts of surgery on body image and sense of femininity (e.g. Rosenberg et al., 2013). Those who recognise they are overestimating their risk may still feel a responsibility ‘to do something’ if they have the option to and lean towards more ‘aggressive’ risk-reducing options. Braude et al. (2017) also highlighted that some women may be motivated to pursue surgery to eliminate the anxiety associated with mammograms and biopsy procedures. Indeed, Beesley et al. (2013) suggest that contralateral ‘risk-reducing mastectomy’ is mainly performed for psychological reasons in and of itself, i.e. to reduce patients’
worry about cancer (rather than objective clinical risk) and for reasons of breast symmetry.

Women who are at population/near population risk of developing breast cancer are generally not viewed as being medically suitable for risk-reducing surgery. The difficulty is that, despite the fact that the risk is relatively low, the personal consequences of developing breast cancer, especially if it is not identified at an early stage, are highly significant. As highlighted above, some ‘feel bound to do all that is possible now to prevent future harm’ (van Djik et al., 2008, p.2362), and to reduce the fear of not doing all they can and possible associated self-blame (Brown et al., 2017). It is therefore understandable that women with a cancer history might seek to reduce any such risk.

Regarding the question ‘does surgery reduce anxiety?’ risk-reducing surgery has been associated with significantly reduced cancer worry (Frost et al., 2000; Heiniger at al., 2014), cancer-related thoughts (Bresser et al., 2007), and general distress (den Heijer et al., 2012). However, the majority of research is in those with a high clinical risk of developing breast cancer. Furthermore, as Fielden et al. (2017) highlight, ‘the dilemma hinges on the ethical question as to whether and when it is appropriate for clinicians to provide invasive, and even surgical, responses to psychological need’ (p.8), especially as there are a range of evidence-based psychological therapies for anxiety (for example Cognitive Behaviour Therapy and Acceptance and Commitment Therapy have been shown to be successful at treating health-related anxiety and fear of cancer recurrence: e.g. Antoni et al., 2006; Lengacher et al., 2014; Montesinas & Luciano, 2016; Sheard & Maguire, 1999).

Furthermore, the procedure is irreversible, with some studies highlighting that over 50 per cent of women experience one or more complications, including infection and implant loss (Arver et al., 2011), pain and numbness, and other negative impacts on aspects of quality of life, such as body image and sexual satisfaction (Bresser et al., 2006; Brandberg et al., 2008; Frost et al., 2005; Gahm et al., 2010; Geiger et al., 2006; Van Oostrom et al., 2003). There are therefore questions regarding whether surgery is an appropriate option for addressing anxiety in those not in the high risk group.

In summary, where it is clear that the main motivations for seeking surgery are primarily related to anxiety or in relation to traumatic impact of the cancer experience, the individual should be offered the opportunity to consider a referral for psychological assessment and evidence-based psychological interventions. It is important that psychological therapy is available in a timely manner should they want it, with a psychologist with appropriate expertise and experience in working in cancer services.

In exceptional circumstances, the multidisciplinary team may make a decision that elective removal of healthy breast tissue is supported for a woman who is not considered to be at heightened risk of developing a further primary cancer (e.g. mastectomy of contralateral breast/mastectomy of affected breast following therapeutic wide excision), for example where a woman is choosing not to have more complex reconstructive surgery on the affected breast but would like to have greater symmetry. Although in these cases the individual would not fall within the risk-reducing pathway (or these risk-reducing surgery guidelines) referral to
a specialist psychologist in psycho-oncology services would still be appropriate. In this situation the referrer must be clear whether they are requesting either a) an in-depth psychological assessment in relation to elective breast procedures (if these are commissioned and medically recommended in the clinical service) b) psychological assessment and support relating to complex factors (e.g. in relation to body image; cancer-related anxiety; traumatic memory of cancer treatments).

3.5.3 The role of the multidisciplinary team where decisions are complex
Given the complexity of the decision-making process for this group of women, Basu et al. (2015) advocate that all women considering contralateral risk-reducing mastectomy should be considered in a multidisciplinary setting. The patient’s reasons for requesting surgery should be carefully assessed and discussed in the light of her objective risk of contralateral breast cancer, influence on survival chances, risks and benefits of the additional surgery and the alternative options around surveillance and imaging. The multidisciplinary team will make a decision based on national guidance and local commissioning arrangements.

3.5.4 Complex decision-making and immediate contralateral surgery
As described in 3.2.2 there are some women diagnosed with breast cancer, who are awaiting treatment and request contralateral risk-reducing mastectomy at the time of initial surgery to treat the cancer.

There is a huge amount for women to adjust to at this early stage, including making sense of their diagnosis and treatment options. It is likely that they will be experiencing an array of strong emotional reactions, including shock and fear. They may be employing adaptive defences such as denial to filter the large amount of information and emotional demand (Brennan, 2004). In this situation, the individual may benefit from help in maintaining those adaptive responses which will enable them to manage their emotions whilst supporting them to consider and process the information about likely clinical risk (of a new cancer).

Due to the necessary time limit in operating on their breast cancer, there is an urgency to evaluate and assess the suitability for a contralateral risk-reducing mastectomy (CRRM) alongside a therapeutic mastectomy so there are additional time constraints on the decision-making process. Basu et al., (2015, p.4) highlight:

‘Nationally defined targets for prompt treatment following a diagnosis of breast cancer may impact on the shared decision-making process by limiting the time available for careful consideration of the pros and cons of CRRM. For the majority of patients, it is probably in their best clinical interest to defer any decision about CRRM until after their primary cancer treatment has been completed. This “cooling off period” minimizes the risk that they make a decision for CRRM as a knee-jerk reaction at a time when they are emotionally vulnerable.’

Thus, if there is any concern or doubt over the patient’s suitability to proceed with a risk-reducing mastectomy (e.g. someone is experiencing traumatic reaction to their diagnosis) it may be helpful for them to consider the pros and cons of having immediate contralateral mastectomy versus delaying elective surgery until they are in a more settled emotional state to review surgery. This approach would also allow time to consider the various reconstructive options.
Basu et al. (2015) do however highlight exceptions to this recommendation, including patients with a known BRCA mutation who may have made a decision previously to undergo bilateral mastectomies for risk-reducing reasons in the event of a cancer being diagnosed. In the case of contralateral risk-reducing surgery, the nature of possible reconstructive options may also influence the decision-making process and the speed at which it happens. For example, in the case of transverse rectus abdominus muscle/deep inferior epigastric artery perforator (TRAM/DIEP) flap reconstruction, abdominal tissue can only be used on one occasion, and in these instances a woman may seek to have contralateral surgery at the same time as the therapeutic mastectomy.

The above issues highlight the complexity of decision-making in this field and the associated benefits of women having the opportunity for timely discussion of their options with a specialist psychologist.
4. The role of psychologists as part of the patient’s decision-making process

4.1 Guidance recommendations

National guidance which highlights the importance of psychological assessment and support during the clinical pathway, including:

*NICE guidance CG164 (2013) ‘Classification and care of people at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer’*

- Pre-operative counselling about psychosocial and sexual consequences of bilateral risk-reducing mastectomy should be undertaken.
- Support mechanisms (for example, risk counselling, psychological counselling and risk management advice) need to be identified, and should be offered to women not eligible for referral and/or surveillance on the basis of age or risk level who have ongoing concerns.
- Care of people in secondary care (such as a breast care team, family history clinic or breast clinic) should be undertaken by a multidisciplinary team and should include access to psychological assessment and counselling.

The Association of Breast Surgery (ABS) and British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS) *Oncoplastic breast reconstruction guidelines for best practice* (Rainsbury & Willett, 2012) recommends an agreed strategy for psychological assessment and management as part of the decision-making process and highlights the importance of psychological support post-operatively and after discharge. The document states that ‘Where complex psychological difficulties are identified, referral to more specialised psychology services will be required’ (p.14).

Research on the role of psychologists in UK breast surgery teams is sparse. However, an Australian study (Braude et al., 2017) highlighted the role as including:

- Assessment of psychological wellbeing and mental health (including assessment of mental capacity).
- Ensuring informed decision-making by checking understanding of procedure and associated risks and benefits (and highlight areas where the patient requires further clarification).
- Exploring physical expectations (e.g. regarding cosmetic outcome, change in sensation) and psychosocial expectations (e.g. impact on relationships).
- Preparation for the procedure, including timing and accessing social support.
- Considering factors that influence and promote post-surgery recovery.

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3 https://www.nice.org.uk/Guidance/CG164
4 British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS) Oncoplastic breast reconstruction guidelines for best practice
   www.associationofbreastsurgery.org.uk/media/23851/final_oncoplastic_guidelines_for_use.pdf
Braude et al. (2017) also suggest that:

‘Psychological consultation could potentially reduce time demands on surgery and facilitate more informed decision making by providing a forum for discussion of emotional issues, decision-making, and assisting the patient to identify questions for their surgeon. Subsequently, it may reduce the need for long-term psychological intervention following mastectomy, and therefore result in a reduction to overall healthcare costs. As such, pre-surgical psychological consultations are potentially cost-effective in the risk-reduction setting’ (p.106).

Psychologists are trained to help patients explore the personal meaning and impact of their decisions and to include their wider interpersonal and environmental context, as well as the impact on their health or risk to health, when making decisions. A core skill of the psychologist, especially in complex cases, is their ability to integrate varied information into a formulation, which is described by the DCP as ‘the summation and integration of knowledge that is acquired by an assessment process that may involve psychological, biological and systemic factors and procedures’ (Johnstone, Whomsley, Cole & Oliver, 2011). Psychologists will also draw on their training and expertise in assessment of mental capacity to make decisions. (Department of Health, 2005; The British Psychological Society, 2005).

4.2 Psychological theory

4.2.1 Decision-making theory

The basic premise of decision-making theory is that individuals have limited thinking capacity so need to simplify what they are doing to meet the demands of having to process relatively large amounts of information, often under pressure. There is a large body of research to indicate that ‘failures’ in decision-making arise when people are anxious: firstly, people in an anxious state pay more attention to threat-related information and secondly they negatively interpret any information that is actually uncertain or ambiguous (Hartley & Phelps, 2012). van Dijk et al., 2008 notes that ‘in decisions that carry a heavy emotional burden people act more rigidly and tend to neglect trade-offs between costs and benefits’ (p.2362).

Brown et al (2017) examined how decisions about risk reducing breast surgery are made and found the following:

- Women typically made their decision on emotional grounds (to reduce the fear of not doing all they can) before an assessment consultation.
- Choosing risk-reducing surgery was largely a decision that was made easily unless patients had fears of the procedure itself. Several used the term ‘no brainer’ to describe a ‘decision’ that barely required consideration. Many described deliberation after the decision.
- Patients seeking risk-reducing surgery were motivated by fear of breast cancer, and the need to avoid potential regret for not doing all they could to prevent it.
- They suggest that when choices for risk-reducing surgery are made emotionally these can be respected as autonomous decisions, provided patients have considered objective risks and benefits.
- Drawing on psychological theory about how people do make decisions, as well as normative views of how they should, Brown et al. (2017) propose that psychologists can guide consideration of risks and benefits even, where necessary, after patients have opted for surgery. Thus ensuring that the decision is reviewed in a ‘rational’
way and can be considered a good decision taking into account normative criterion.

They concluded that it is important that patients are provided with the opportunity to reflect on their decision and to consider objective risks and benefits with a skilled practitioner. Specialist psychologists are well placed to support individuals with the process of decision-making especially when faced with complex decisions in pressurized situations, such as in the case of risk-reducing surgery (Tversky & Kahneman, 1981; Vohs et al., 2008; Zajonc, 1980).

4.2.2 Decision aids
Edwards & Elwyn (2006; 2009) describe the use of decision aids to support patients through the decision making process. These enable clinicians to provide a full account of the evidence base for a procedure, whilst considering the individual’s needs, preferences and values (Durand et al., 2015). Of note, a Cochrane review (Stacey et al., 2014) found that when patients use decision aids in a health care setting (not specific to risk reducing surgery) they:

- Improve their knowledge of the options;
- Feel more informed and more clear about what matters most to them;
- Have more accurate expectations of possible benefits and harms of their options;
- Participate more in decision-making;
- Have better communication with their health practitioner.

OptionGrid has a number of decision tools to support women making decisions around treatment, including reconstructive surgery for women who have had cancer (see Appendix 6i for an example). Another tool is the Decision Conflict Scale (O’Connor, 1995) (see Appendix 6ii) though this has not been tailored to decisions around breast surgery and reconstruction. There is preliminary data that the PEGASUS tool, an intervention to facilitate shared decision-making with women contemplating breast reconstruction, helped patient’s prepare for the surgical consultation and increased their trust in their surgeon (Harcourt et al., 2016).

Additional research is required on developing specific decision aids that could support individuals with complex decisions around whether, when, and how to proceed with risk-reducing surgery.

4.3 When should a psychologist be involved?
This guideline recommends that psychologists are included in the clinical pathway for all patients who are considered by the multidisciplinary team to be medically suitable and eligible for risk-reducing breast surgery, including bilateral and contralateral requests with and without reconstruction. In light of cases where a patient requests an immediate contralateral mastectomy alongside a therapeutic mastectomy, the service should have the provision for a fast-track psychology appointment and follow-up reporting to the surgeon and multidisciplinary team.

The psychologist’s role is to offer specialist psychological assessment and support after the surgical team has decided whether the individual is medically suitable and eligible for this surgical intervention and after they have had the full range of information about surgical options. This information should include genetic testing or comprehensive family history
screening and calculation of their likely risk of developing breast cancer (including those seeking immediate contralateral surgery alongside their therapeutic mastectomy) as well as an explanation of whether surgery would or would not likely influence their survival prospects (Basu et al., 2015). In cases where this information has not yet been gathered, it is important for the psychologist to refer back to the referrer and multidisciplinary team to gain this information. This timing in the patient’s pathway reduces the likelihood of the psychologist being seen as a ‘gatekeeper’ to surgery and reduces disappointment, from a patient’s perspective, of discussing the procedure in depth with the psychologist and it then being declined by the medical team. (see Appendix 1 for a sample pathway).

As highlighted in Section 1. Scope of the Guidelines, it is important to stress that it is not the psychologist’s role to make a decision about when a patient should be offered risk-reducing surgery as a treatment option. This decision lies with the multidisciplinary team, based on national policy (e.g. NICE guidance and local commissioning arrangements).

A consultation with a psychologist allows the patient an opportunity to discuss a range of issues affecting decision-making, to explore concerns, anxieties and the psychological challenges of risk-reducing breast surgery. These discussions can facilitate post-operative psychological adjustment, can help with the quality of the decision-making and help to determine what additional information is needed to make an informed choice (Tan et al., 2009).

The number of sessions required will vary, with the majority requiring one session only, but in some cases, further sessions may be indicated, both as part of pre-surgical consultation as well as any additional psychological support that may be required in preparation for, or instead of, surgical treatment.

Patenaude et al., (2008) reported that more than half of women in their study felt that a psychology consultation would be useful and even more felt that post-surgical consultation would be useful. In light of this we would recommend that all patients be offered a follow-up session following surgery, to review how they are coping with their recovery and whether any additional psychological support may be beneficial.

4.4 Training and Qualifications

The psychological consultation should be carried out by a HCPC registered practitioner psychologist. It is recommended that the psychologist has completed the Level 3/4 Induction to Clinical Practice in Oncology and Palliative Care (BPOS-SIGOPAC-BPS Publication, 2011) and holds:

- Specialist knowledge of breast cancer and treatments;
- Basic knowledge of surgical procedures and likely outcomes and risk complications;
- Understanding of breast cancer-related genetic markers;
- Understanding of statistics and ways of discussing these in accessible ways.

It is important to acknowledge that this area of specialty is complex and demanding in a number of ways and can raise personal and professional questions for the psychologist. It is therefore recommended that psychologists have opportunities to reflect on their practice in supervision with a psychologist with expertise in this area.
5. The psychology consultation

5.1 Referral process
It is recommended that a referral to psychological services is made after the clinical team has made the decision that risk-reducing breast surgery is a medically suitable procedure. As indicated above, it is recommended that this is after they have received sufficient information about surgical options.

5.1.1 In cases where women are requesting an urgent contralateral mastectomy
When the assessment is preparing a woman for immediate contralateral surgery alongside treatment for a breast cancer, there is often a very short time span to arrange an assessment and often very limited options for psychological support/follow-up. It is recommended that the emphasis of the consultation is on preparation for surgery; capacity to consent and preparedness for practical consequences of the surgery. If the psychologist has marked concerns about the patient’s preparedness for surgery, there needs to be a fast-track mechanism to feed this back to the MDT for further consideration for appropriateness of elective mastectomy alongside therapeutic breast surgery.

5.2 Recommendations for how the surgical team can introduce the aims of the psychological consultation to patients
All patients being offered/requesting risk-reducing mastectomy should be informed that a meeting with the psychologist is a standard, routine component of clinical care prior to undergoing surgery.

The psychological consultation should be introduced as an opportunity to discuss a range of issues affecting decision-making, to explore concerns, anxieties and the psychological challenges of risk-reducing breast surgery. Surgeons should communicate that the psychology appointment is an opportunity for the patient to spend time thinking through their motivation for surgery, and feelings and expectations regarding the outcomes of surgery. It should be explained that the psychologist will ask questions about the individual’s past and current wellbeing by way of considering psychological readiness for surgery and potential pre- and post-surgical support needs. It is important however, that psychologists are not seen as the ‘gatekeepers’ to surgery, but rather are there to support and facilitate decision-making with the aim of achieving the best possible surgical adjustment.

As the inclusion of psychologists as part of the routine care pathway may differ from previous practice in some services, it may be useful for the psychologist’s role to be explicitly defined to the multidisciplinary team (Braude et al., 2017).

Verbal and written information provided in advance of the psychological consultation (e.g. by the surgeon or sent out with the appointment letter) can help to alleviate anxieties about the psychological consultation and manage expectations.

Written material should include:
1) Information as to why they have been referred to a psychologist and the benefits of talking through the decision-making process;
2) Clarification of the psychologist’s role as part of the risk-reducing/elective surgery process (and what it is not);
3) Information regarding what will happen at the appointment and afterwards (e.g. report/follow-up);
4) Information on confidentiality.

See Appendix 2 for a sample leaflet.

5.2.1 What if an individual declines a psychology appointment?

If a surgeon has recommended psychological assessment and the patient declines the psychology appointment but still wishes to pursue surgery, it is important to explore the reasons why a patient does not wish to attend, and to address any concerns the patient may have. There should be further discussion at MDT if a patient still declines to attend.

5.2.2 What information does a psychologist need in order to support a woman with her decision-making?

- Patient’s consent to meet with the psychologist.
- Formal risk assessment (genetics or family history screen) and confirmation that the patient has been informed of the result (estimated risk of a new breast cancer).
- In certain cases, information about risk of recurrence e.g. if there is high risk of metastatic disease/recurrence which may shape a person’s decision about reducing risk of a new primary breast cancer.
- General health – there may be other health conditions that shape a person’s decision about risk-reducing surgery (e.g. if risk to them is greater/more urgent from another health condition).
- Is a routine or priority appointment required (e.g. in the case for requests for urgent contralateral risk reducing surgery alongside cancer treatment) - with the planned surgery date specified.
- Reason for consideration for surgery (identified genetic mutation/strong family history/personal history/other).
- What has already been discussed with the patient (e.g. quantitative risk v patient perceived risk, risk reduction v elimination, discussion regarding surgery and reconstruction options).
- Whether the surgeon feels that this is a clinically recommended option. Any clinical concerns (‘red flag’ events) should be made clear.
- Other relevant medical, social, psychological issues.
- If there is a personal history of breast cancer, information regarding cancer diagnosis and treatment is required.

See Appendix 3 for a sample referral form to psychology.

5.3 Who is invited to the consultation?

In addition to the woman herself, she may wish to bring a partner or close family member. The involvement of significant others during the decision-making process may help to:

- Increase their awareness of the potential psychological, social, and physical challenges of surgery.
- Develop realistic expectations of the surgical process, outcomes and risks associated with surgery.
- Consider and plan their involvement in practical and emotional support in relation to surgery.
However, it is important for the psychologist to spend some time with the patient on her own, as there may be certain issues that the patient would feel more able to talk about without a partner or family member there. If there are concerns regarding a woman’s ability to voice her preference safely with a significant other present, the psychologist is strongly advised to make a decision to meet with the woman on her own and discuss whether to involve others.

We recommend that sessions are conducted without children present to enable the woman to discuss her thoughts and feelings more freely without concern about what the child hears, and for her to be able to focus as fully as possible on the discussion.

This guidance recommends that the consultation should not be carried out in a group format with several women together. Whilst women going through risk-reducing surgery may benefit from talking to others who have been through the process, the issues relating to decision-making that are discussed in the psychological consultation are complex, sensitive and personal to them.

### 5.4 Format of the psychology consultation

Typically, the consultation will take 1–2 sessions of approximately one hour duration but there should be provision for additional sessions as recommended by the psychologist. It is important that the psychologist reiterates the aims of the consultation as outlined above and clarifies that information from the meeting will be used to prepare a report for the patient and for the surgical team. A leaflet sent to patients prior to this appointment explaining the purpose of the meeting is likely to help the patient have clearer expectations regarding this aspect of their care.

We would recommend that the psychological consultation cover the themes summarised below and outlined in the Table of Recommended Themes (Appendix 4.1) and Interview Template (Appendix 4.2):

- **Motivation for surgery** (e.g. why now?);
- **Background factors** (e.g. route to finding out about risk; understanding about level of risk);
- **Understanding of procedure(s)** (e.g. awareness that risk is reduced not eliminated; understanding about possible complications of surgery, specific issues relevant to reconstruction);
- **Body image and intimacy** (e.g. thoughts and feelings about breasts and body);
- **Reaction of others** (e.g. have they talked about concerns with significant others);
- **Expectations of life post-surgery** (e.g. going swimming; physical intimacy);
- **Psychological issues** (e.g. impact of past stressors on emotional wellbeing; resilience);
- **Weighing up the pros and cons** (including clarifying capacity to give consent);
- **Feedback, recommendations and next steps** (e.g. support options; report to referrer).

*It is important NOT to consider these as indications/contraindications for surgery but as important areas to inform the complex process of decision-making.*

In some cases, a more formal mental capacity assessment may be indicated. It is the responsibility of clinicians to provide the information in an appropriate form in order to optimise understanding. The individual needs to be able to understand the information and retain it for long enough to make the decision in question. Psychologists should consider the following issues in evaluating whether someone has the ability to understand and weigh up the information:
- Appreciation of the wider consequences of the decision on themselves and others;
- Evidence of reasoning processes;
- Consistency between expressed beliefs and decision reached;
- Ability to weigh up the risks and benefits of different options;
- The possible influence of pressure from others;
- The importance to the person of religious and cultural beliefs that may have influenced and/or may account for the decision taken.

Readers are advised to refer to The British Psychological Society (2005) and Department of Health (2005) mental capacity guidance for further information regarding these assessments.

5.5 Self-report measures
Self-report measures can be used as an adjunct to the psychological consultation and use of decision aids, for clinical and audit purposes. They should not be used as a ‘stand-alone’ procedure or for diagnostic purposes but to aid the process of information gathering. There are presently no psychometric measures developed specifically for patients considering risk-reducing surgery. However, typical domains of measurement and self-report measures that have been suggested by clinicians in the field are detailed in Table 2.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Example self-report measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress</td>
<td>Hospital Anxiety and Depression Scale (HADS) (Zigmond &amp; Snaith, 1983), PHQ 9 (Depression screen) and GAD 7 (Anxiety screen) General health questionnaire (GHQ 28) (Goldberg, 1978) CORE-10 (Barkham et al., 2013)</td>
</tr>
<tr>
<td>Quality of life/function</td>
<td>SF-36 (Ware &amp; Sherbourne, 1992) WHOQOL-BREF (World Health Organisation quality of life measure)</td>
</tr>
<tr>
<td>Cancer worry</td>
<td>Cancer Worry Scale (Custers et al., 2014)</td>
</tr>
</tbody>
</table>

When making a decision about the inclusion of self-report measures as part of the consultation, a number of factors should be considered (Sogg et al., 2016):
- The reliability and validity of any potential measures, including the existence of empirically established norms.
- The extent to which the measure provides additional, relevant information beyond what can be gathered during the consultation.
- The costs of any potential measures, including financial, length of time taken to be completed and level of personal intrusiveness.
If the psychologist makes a clinical decision to use self-report measures as part of the consultation, we would recommend they advise patients in advance of their appointment that they will be invited to complete questionnaires, and the rationale for this as individuals may otherwise see the consultation as having a gatekeeping role, and thus be concerned about how the measures are used. We recommend that the psychologist provide feedback on the questionnaires to the patient.

MDT clinicians may be unfamiliar with these measures and thus we would recommend the psychologist provide a descriptive account of what they suggest in the summary letter rather than including specific numbers/clinical cut-offs to reduce the likelihood that these will be misinterpreted.

5.6 Possible outcomes of the psychological consultation
At the end of the consultation the psychologist should summarise the meeting and clarify outcomes of the consultation with the patient, for example:

a) Suitable for surgery from a psychological perspective with recommendations to surgical team and patients for areas for discussion in the next surgical appointment (e.g. expectations of cosmetic outcome).

b) Recommendation that surgery be delayed so that further psychological assessment and additional intervention/support can be conducted, for example due to the following:
   - In the case of psychological unpreparedness, for example, where the individual has not fully thought through their decision and/or may need further information;
   - Where the individual demonstrates limited understanding of the impact of surgery on their cancer risk and/or the individual demonstrates limited understanding of the physical and emotional impact of surgery;
   - Where the individual lacks support and personal coping strategies to manage the surgery and any potential negative outcomes;
   - Where the individual lacks confidence in their decision to proceed with surgery, or where they are basing their decision primarily on pressure from others;
   - Significant emotional distress that affects an individual’s ability to make informed decisions;
   - Where the individual lacks mental capacity, or where there are concerns over reasoning ability;
   - Where the decision is based primarily on anxiety rather than clinical risk;
   - Where the individual has significant pre-existing body image and/or eating issues that would undermine adjustment post-surgery and influence expectations (Den Heijer et al., 2012).

5.7 The psychology report
We recommend that a summary of the psychological consultation (including patient’s specific hopes and expectations regarding surgery, and any recommendations discussed) should be sent to the patient and copies sent to the referring surgeon, plastic surgeon (if appropriate) and other relevant clinicians (e.g. geneticist, GP) with permission of the patient (see Appendix 5 for examples). This can then be reviewed with the patient in follow-up appointments.
Following the psychological consultation, the individual’s readiness to proceed with surgery should be discussed with the surgical team. If it is agreed that the individual would benefit from some ongoing psychological support, the clinical team should be kept updated of the progress of this work, in line with confidentiality arrangements and local hospital policies.

See Appendix 7i and 7ii for sample reports.

5.8 Follow-up
As mentioned earlier, Patenaude et al., (2008) reported that more than half of women in their study felt that a post-surgical consultation would be useful. We would recommend that all patients be offered a follow-up session following surgery, to review how they are adjusting after surgery and with their recovery and to see whether any additional psychological support may be beneficial, either within the breast care team or within community services.
6. Broader support and resources

The psychologist may benefit from making available a list of resources, including leaflets and online sites.

Individuals considering risk-reducing surgery can benefit from the opportunity to meet and discuss the operation with others who have been through the same process and this is recommended by NICE (1.7.40). From clinical experience, it may be more helpful for them to access this once their medical suitability for risk-reducing surgery has been confirmed.

Possible avenues for support:
- Breast Cancer Care Someone Like Me service5.
- Flat Friends (for women electing not to have breast reconstruction)6.
- National BRCA support group7.
- Local support groups (which may be attached to the breast care and/or Dept. of Plastic & Reconstructive Surgery teams) e.g. Keeping Abreast8.

A recommendation for future research would be to investigate the evidence for the use of resources, support groups, and buddy systems as part of the decision-making process for this population.

As mentioned earlier we recommend, as a minimum, patients be given a leaflet about their psychology consultation prior to the appointment, to explain the purpose of the appointments(s) and allay any concerns (see Appendix 2 for an example). We also recommend that patients are signposted to (and ideally given a hard copy of) the Macmillan booklet on risk-reducing surgery.9

Social media (e.g. Facebook, Twitter and Instagram) is also becoming increasingly popular as a way of women accessing support.

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5 https://www.breastcancercare.org.uk/information-support/support-you/someone-talk/someone-me
6 www.flatfriends.org.uk
7 www.breastcancergenetics.co.uk
8 www.keepingabreast.org.uk
9 be.macmillan.org.uk/be/p-299-understanding-risk-reducing-breast-surgery.aspx
7. Service evaluation: Demonstrating quality and outcomes

A service offering psychological assessment for risk-reducing breast surgery should be able to demonstrate the quality and outcomes of their service in relation to the SIGOPAC Quality and Outcomes Framework (The British Psychological Society, 2015).

The framework focuses on six key domains of service quality:

- Is this service *safe*?
- Is this service *equitable*, while also focused on those most in need?
- Is this service *timely and responsive*?
- Is this service *respectful, collaborative and patient-centred*?
- Is this service offering *effective* interventions?
- Is this service contributing to *efficient* multidisciplinary care?

This information may be gathered through activity data (e.g. waiting times), patient feedback forms and audit. An example is given in Appendix 6\(^\text{10}\).

\(^{10}\) http://shop.bps.org.uk/demonstrating-quality-and-outcomes-in-psycho-oncology.html
8. Recommendations for future research

Although requests for risk-reducing surgery have increased over recent years, the evidence base regarding surgery and biopsychosocial outcomes remain in relative infancy. There are therefore numerous avenues where robust research would help to develop a clearer evidence base to guide discussions with individuals considering this surgery. These include:

- What is the level of acceptance of the offer of a standard psychological consultation as part of pre-surgical decision-making?
- Does being helped to reflect on decisions influence patients’ decisions? Does the psychological consultation influence patient satisfaction with their decision?
- What are the psychosocial outcomes in risk-reducing surgery, when the decision is primarily based on other factors e.g. cancer worry, cosmesis, pain rather than objective risk?
- Is it possible to identify psychosocial risk factors which are associated with a poorer psychological outcome in risk-reducing surgery?
- Is it possible to identify psychosocial protective factors which can enhance psychosocial outcome in risk-reducing surgery?
- How can clinical services best support patients to make their decision regarding whether, when, and how to proceed with risk-reducing surgery?
- What content, medium, and mode of delivery of information about risks and benefits of risk-reducing surgery is most effective in supporting individuals to make an informed decision?
- Can tailored psychometrics facilitate assessment (e.g. of psychological preparedness)?
- What decision aids would improve satisfaction and reduce regret for this specific population?
- Are there any additional challenges in the younger age group (i.e. <30 years), for example in adjustment to body image and impact on intimacy?
- Although only a small group, little is known about the prevalence of men requesting risk reducing surgery and what the specific challenges might be for them from a psychosocial perspective.
9. References


Bresser, P.J.C., Seynaeve, C., Van Gool, A.R et al. (2007). The course of distress in women at increased risk of breast and ovarian cancer due to an (identified) genetic susceptibility who opt for prophylactic mastectomy and/or salpingo-oophorectomy. *European Journal of Cancer, 43*(1), 95–103.


Patenaude, A.F., Orozco, S., Li, X. et al. (2008). Support needs and acceptability of psychological and peer consultation: Attitudes of 108 women who had undergone or were considering prophylactic mastectomy. *Psycho-Oncology, 17*(8), 831–843.


10. Appendices – contents

Appendix 1: Sample pathway for psychology for women considering risk-reducing surgery
Appendix 2: Example patient information for women considering risk-reducing mastectomy
Appendix 3: Sample referral form to psychology
Appendix 4.1: Recommended themes for the initial psychology consultation
Appendix 4.2: Sample psychological consultation semi structure interview schedule
Appendix 5: BPS Demonstrating Quality and Outcomes checklist
Appendix 6: Example decision tool: Breast cancer reconstruction after surgery for cancer – options
Appendix 7i: Sample psychology report (example 1)
Appendix 7ii: Sample psychology report (example 2)
Appendix 1. Sample pathway for psychology for women considering risk-reducing surgery¹¹

¹¹ (To be adapted according to local service provision)
Appendix 2. Example patient information for women considering risk-reducing mastectomy

Patient information leaflet
Breast care psychology appointment for women considering elective/risk-reducing breast surgery

Considering elective risk/reducing breast surgery
Some women have a higher than normal risk of breast cancer. This can be because they have inherited a particular gene (e.g. BRCA-1 or BRCA-2), or because there is a history of breast cancer in their family. When a high risk of developing breast cancer is identified, the option of an elective mastectomy may be considered to reduce the risk of someone getting a new diagnosis of breast cancer. This is an operation where one or both healthy breasts are removed.

Although this does not remove all risk of developing breast cancer, it reduces the risk of developing cancer for those at high risk, but is not a treatment for reducing recurrence of a previous breast cancer. The procedure is not usually recommended for those with a low risk of developing breast cancer.

The decision is a serious one, because it is a big operation that cannot be reversed, and like all surgery has its own risks. There are additional considerations, such as whether to have a reconstruction or whether to wear prostheses.

You may already have been considering your choices for some time. You may also have talked to your partner and your family. You may have spoken to a Genetics Counsellor and Breast Care Surgeon about your risk of breast cancer, and how much elective/risk-reducing breast surgery can reduce this risk. You may have talked with the Breast Care Surgeon and Plastic Surgeon about the different options (e.g. for reconstruction) and the risks and benefits of the operation(s).

Why do I need to see a breast care psychologist?
At first it may seem strange when your consultant surgeon refers you to a psychologist to talk about your consideration to have risk-reducing/elective mastectomy. Some people worry that their decision will be challenged, or that the psychologist has to make sure that they are not ‘crazy’ for wanting, or not wanting to take this option, or that they have to try and convince the psychologist that they really want this surgery to be able to have it.

This is not the case – seeing a psychologist is a normal part of the preparation for this procedure for all patients. The psychologist you see specialises in helping people with physical health concerns and is part of the breast care team. They are there to support you, and to help make your decision and experience as easy as possible.

How will seeing the breast care psychologist help me?
Every woman considering elective/risk-reducing breast surgery will be referred to see the breast care psychologist as part of their routine care with the Breast Care team.

The psychologist will provide a ‘sounding board’ to help you with the process of
decision-making. They will give you time to explore your options (including pros and cons), motivations (e.g. to reduce risk, to reduce worry, to alter the appearance of your breasts), expectations, and your emotional, social, and physical wellbeing. Sometimes it is difficult to talk with your partner or family because they have their own fears and worries, and their own opinions about what you should decide. The appointment with the psychologist is to help you feel assured that you have made the best decision for you.

The psychologist can also help you think about how you prepare for surgery and recovery, any support that you may need, and about decisions about reconstruction. On occasions, where women are experiencing cancer-related worry, the psychologist may recommend you access some support for this before making a decision about proceeding with surgery.

**What happens at the appointment?**

The initial appointment will be at xx Hospital and will usually last around 50 minutes. It will give you an opportunity to talk about your experiences, including how your breast cancer risk was identified and the impact you feel it has had on you. You can talk about your thoughts, feelings, worries and motivations for having surgery, including your expectations about surgery and the recovery process, and identify any further information or support you may need. Sometimes the psychologist will recommend you meet more than once and on occasions may offer additional support.

You do not have to have made a decision already. This session is to help you think about which decision is best for you, but there is absolutely no time pressure. You can think about it as long as you need and ask for more sessions with the psychologist if you feel this would be helpful. You will be asked to complete some questionnaires before your appointment and will have the opportunity to talk through the results of these.

Following the appointment the psychologist will write a brief letter summarising the main issues discussed and any recommendations. You will receive a copy of this alongside the breast care team and your GP, and anybody else you think it would be helpful to send a copy to.

**A patient’s perspective**

“When I was told I needed to see a psychologist I recall feeling a bit defensive! I was worried that the psychologist might try and talk me out of it, or to say I was too emotional. I can honestly say that I was more worried about that appointment than I was seeing both my surgeons. I could not have got it more wrong if I tried!

From the moment I saw the psychologist, I was totally reassured. We talked through my hopes and expectations for surgery, and she really did help me confirm I had made the right decision for all the right reasons. The support did not stop there either, she gave me so many coping tools which enabled me to sail through my operation and recovery, and I could not have done it without her. I now know why this wonderful service is necessary; it is such an integral part of the journey.’

Feedback from xxx, who had bilateral risk reducing mastectomy with reconstruction.

*This leaflet is based on an information leaflet produced by The Pan Birmingham Cancer Network, and adapted by Southmead Hospital with thanks for their permission to use this.*
### Appendix 3. Sample referral form to psychology

**Risk-reducing surgery: Psychology referral**

<table>
<thead>
<tr>
<th>Patient addressograph OR</th>
<th>Referring surgeon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>Tel No</td>
<td></td>
</tr>
<tr>
<td>D.O.B.</td>
<td></td>
</tr>
<tr>
<td>MRN</td>
<td></td>
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<td></td>
<td></td>
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</tbody>
</table>

**Referring surgeon**

- Other professionals involved:
- GP name / practice
- Today's date

**Patient has been discussed at RRM oncoplastic MDT on __/__/____ (date) and agreed that RRM is a recommended option from a medical perspective □ (please tick)**

<table>
<thead>
<tr>
<th>This referral is:</th>
<th>□ Urgent (Only for patients with current unilateral ca. requesting cRRM)</th>
<th>□ Routine</th>
</tr>
</thead>
</table>

**Clinical risk:** Patient has had formal risk assessment via

- Genetics □ or Family History clinic □ and been given the result Y/N

<table>
<thead>
<tr>
<th>Please tick 1 per column</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 yr risk</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Near Population</td>
</tr>
<tr>
<td>Moderate</td>
</tr>
<tr>
<td>High</td>
</tr>
</tbody>
</table>

□ Known genetic defect – please give details: ........................................................................................................

□ Strong family history but no identified genetic defect

□ Previous breast cancer and requesting contralateral RRM

□ Current unilateral cancer, requesting contralateral RRM (URGENT)

  Planned date of surgery: ..........................................................

  (this must be filled in for referral to be triaged as urgent)
REFERRING SURGEON: Please ensure all sections are completed

Relevant medical information, incl. details of reconstruction options discussed, likely procedures, timing, etc.

Please tick any areas discussed with your patient:
- Patients calculated cancer risk vs perceived risk
- Current Guidelines re RRM and risk
- Level of protection offered by surgery (i.e. Not 100% protective)
- Reconstruction options
- Surgical complications incl. potential flap/implant loss
- Altered breast appearance
- Loss of sensation / function
- Surveillance options

Has patient been referred to plastic surgery? Y/N
If yes please give details as appropriate

Name of breast care nurse: _____________________

Any relevant emotional / social issues?

Any clinical concerns (red flag events)?

Please enclose any clinic letters that may be useful for the psychology consultation

Please return this form to:

Admin contact and address

<table>
<thead>
<tr>
<th>e-mail:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tel:</td>
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<tr>
<td>Fax:</td>
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</table>

The Psychology team will liaise directly with the patient and let you know how we get on. If you would like to discuss this referral before then, please contact [Practitioner Psychologist] on [phone number / email]
# Appendix 4.1 Recommended themes for the initial psychology consultation

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Possible areas to explore</th>
<th>Evidence base</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motivation for surgery</td>
<td>Women with breast cancer may have complex reasons for requesting risk-reducing mastectomy, which may include having a gene mutation, family history, worry about a new/further diagnosis of cancer, protecting children from the experiences they have had, anticipated regret of having cancer in the future, fear of going through treatment e.g. chemotherapy, mistrust of available surveillance options, being offered DIEP reconstruction as a 'one only' option, approaching age at which a close relative developed breast/ovarian cancer, breast pain, breast asymmetry. It is important to explore the range of factors that may be leading her to consider this option, including whether the decision is internal (i.e. woman's own decision) or external (i.e. influenced by views of partner, surgeon). The reasons for choosing risk-reducing surgery are likely to vary significantly for women with a personal experience of breast cancer (whether present or past) or those with genetic markers considering bilateral surgery. This open-ended exploration can give context to decision-making and some of the emotional challenges they have faced.</td>
<td>Meiser et al. (2000); Beesley et al. (2013); Basu et al. (2015); Van Driel et al. (2014); van de Djik et al. (2008).</td>
</tr>
<tr>
<td>Main themes</td>
<td>Possible areas to explore</td>
<td>Evidence base</td>
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Main themes | Possible areas to explore | Evidence base
--- | --- | ---
Understanding of procedure and expectations of outcome (e.g. understanding about risks and complications of surgery) | ■ Explore their ability to relay information on possible risks and complications and how they anticipate they would cope with these.  
■ Understanding and feeling regarding scarring, including in breast area and donor site (if applicable), changes in sensation, and likely aesthetic and physiological outcome.  
■ Possible areas where they would benefit from clarification, additional information or support.  
■ Description regarding expectations of outcome (including specificity).  
■ Degree to which individual has been proactive regarding information seeking and relevant behaviour change (e.g. re: weight loss, smoking). | NICE guidance CG164 (2013).  
Studies tend to report high levels of satisfaction post-surgery, with no change to, or even enhanced quality of life. The most common finding is a reduction in breast cancer worry and anxiety (Frost et al., 2000; Van Oostrom et al., 2003; Altschuler et al., 2008; Metcalfe et al., 2004; Brandberg et al., 2008; Frost et al., 2005; Nekhlyudov et al., 2005; Bresser et al., 2006; Isern et al., 2008; Frost et al., 2011).  
Some research outcomes report complications (up to 50% of cases for some procedures, e.g. DIEP) poor cosmetic outcomes, diminished sense of sexuality, poor body image, a decreased sense of femininity and a perceived negative perception of partners. (Van Oostrom et al., 2003; Geiger et al., 2006; Brandberg et al., 2008; Bresser et al., 2006; Frost et al., 2005).  
Despite dissatisfaction with appearance, women may still have a high level of satisfaction with life and not regret their decision. It may be that women are less concerned about a negative change to appearance or intimate situations as they consider this a less important problem to have than to live with a high risk of breast cancer (Brandberg et al., 2008).  
The variability amongst individuals emphasizes the importance of thorough pre-operative information and discussion of surgery, likely outcomes and possible complications to enable women to make an informed decision (Hagen et al., 2014).  
Patients should be fully informed of the risks and benefits of risk-reducing mastectomy. This is the responsibility of the surgical team but will be explored within the psychology consultation.
<table>
<thead>
<tr>
<th>Main themes</th>
<th>Possible areas to explore</th>
<th>Evidence base</th>
</tr>
</thead>
</table>
| **Body image, intimacy & reactions of others** | ■ Impact of surgery on body image and intimacy.  
■ Thoughts and feelings about breasts and body (positive/negative).  
■ How important is their appearance to sense of self?  
■ Thoughts re: saying goodbye to breast(s) (anticipated loss/coping e.g. breast feeding, pleasure, intimacy).  
■ Thoughts regarding breast reconstruction and options (immediate/delayed; type).  
■ Discussion with partner? If not in a relationship, views around this? | Research to date highlights that whilst surgery tends to reduce worry about cancer/relief, the area that can cause concern for women is about change in body image and sexuality.  
Current body image dissatisfaction can be associated with poor body image outcomes. Therefore, exploration of coping styles and body image perception before PM/BR may help to identify vulnerable women who may benefit from additional support (Den Heijer et al., 2012). |
| **Preparing for surgery** | ■ Ideas for preparation and degree that patient is able to reflect on this; proactive re: behavior change (e.g. weight loss and smoking) | |
| **Expectations of life post-surgery (e.g. going swimming, physical intimacy)** | ■ How do they think life will be different (re: specific/general worry, relationships etc.)  
■ If they went through surgery and still got cancer, how might they feel?  
■ Quality of life – ask them to imagine certain situations post-mastectomy e.g. going swimming, intimacy, bottle feeding.  
■ What might help in adjusting to new breasts?  
■ Have they talked about these issues with significant others? What support might they need? Do they feel they have adequate support? Work? | |
<table>
<thead>
<tr>
<th>Main themes</th>
<th>Possible areas to explore</th>
<th>Evidence base</th>
</tr>
</thead>
</table>
| Psychological Issues (e.g. impact of past stressors on emotional wellbeing; resilience) | - Current/past stresses and impact on emotional wellbeing/mental health.  
- Risk issues (current/past).  
- Any treatment or support received? (incl medication).  
- Coping strategies/resilience.  
Some women will have experienced adversity in the loss of a mother or cancer in a close family member.  
Think through what has helped them to cope during these challenging times, or what they have learned about managing their own mental health during previous episodes of anxiety or low mood.  
Explore how proactive the patient is in terms of information gathering, carrying out behavioural goals, attending sessions. | Studies with patients with a BRCA gene mutation have shown that the majority of women report decreased cancer related distress while broader psychosocial functioning does not appear to be significantly affected in a positive or negative way (Frost et al., 2000).  
Post-surgical distress more often related to surgical complications, perceived risk of breast cancer, having young children, and psychiatric history (Van Oostrom et al., 2003; Meyer & Ringberg, 1986; Hopwood et al., 1998; Butow et al., 2005). |
| Weighing up the pros and cons (including clarifying capacity to give consent) | - Capacity to give informed consent (able to retain information, weigh up pros and cons, communicate their decision).  
Understanding pre-existing psychological difficulties, and impact this may have on decision-making (for example, but not limited to mental capacity) and what support someone may need to facilitate process of making an informed decision and informed consent.  
Levels of psychological distress will be an indicator of the need for provision of additional psychological support during the process and post-operatively. | If distress is high enough to impair decision-making, surgery may need to be postponed and it is important that avenues for specialist psychological support are available (Tan et al., 2009). |

N.B. It is important to note that it is hard to generalise directly from research findings due to the variations in methodology between research studies.
Appendix 4.2. Sample psychological consultation semi structure interview schedule

Psychological consultation: Risk-reducing/elective mastectomy

<table>
<thead>
<tr>
<th>[Hospital sticker]</th>
<th>Referred by</th>
<th>Confidentiality explained? □</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient name</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital number</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DOB</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral date</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Today's date</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter to:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referrer/Patient/GP/Plastics/Genetics/other ____________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaires completed? □</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Review patient’s understanding of the appointment and give summary e.g. Part of clinical pathway. Not test/gatekeeping but chance to talk through decision in detail with someone who is not family/surgeon etc.
- Better outcome/satisfaction associated with good preparation;
- Conversation may highlight where people need additional info/support;
- 45 mins–1 hr, may need to meet again to complete process, give overview of areas to be covered;
- Note-keeping, confidentiality (limited e.g. will feedback important points to MDT);
- Any questions at this stage?

Motivation for surgery
- What factors have led to your decision? Why now?

Background factors
- Route to finding out medical risk. Seen by genetics or family history? □ Date ............................
- Patient’s reaction to this? Others reaction to this
- Understanding about level of risk 1) recurrence, 2) new cancer
Understanding of procedure

- How much reading/information seeking have they done about surgery and recovery?
- Awareness of other options?
- Understanding about impact on risk reduction (check expectation ≠ zero)

- Referred □ / seen □ plastic surgeon?
- What is your understanding of options for surgery and reconstruction? Preferences and why.
- Expectations re: Cosmetic outcome (size, shape, scarring, nipples) and sensation

Understanding of risks and complications and how they anticipate they might cope with these

E.g. mastectomy – gen anaesthetic, infection, DVT, wound breakdown, bleeding, pain
E.g. reconstruction – asymmetry, reduced/lack of sensation, scarring, changed appearance/feel, may need >1 procedure

Risk factors: Smoking/weight

<table>
<thead>
<tr>
<th>DIEP recon</th>
<th>Implant recon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haematoma,</td>
<td>Capsular contr.,</td>
</tr>
<tr>
<td>infection, flap loss,</td>
<td>rippling/folds,</td>
</tr>
<tr>
<td>changed/ senation</td>
<td>asymmetry, size,</td>
</tr>
<tr>
<td>breast abdo, blood</td>
<td>implant rejected,</td>
</tr>
<tr>
<td>transfusion, scars,</td>
<td>seroma</td>
</tr>
<tr>
<td>&gt;1 op</td>
<td></td>
</tr>
</tbody>
</table>

- Any experience of previous surgery? Any concerns?
Body image and intimacy
- Research to date highlights that whilst surgery tends to reduce worry about cancer/relief, the area that can cause concern for women is about change in body image and sexuality.
- Thoughts and feelings about breasts and body (positive/negative). How important is their appearance to sense of self?
- Thoughts re: saying goodbye to breast(s) (anticipated loss/coping e.g. breast feeding, pleasure, intimacy).
- What might help in adjusting to new breasts?

Reaction of others
- Have they talked about these issues with significant others? Do they feel they have adequate support? Pressure from others?
- Practical considerations e.g. personal care, childcare, work, other health issues.

Expectations of life post-surgery
- How will life will be different? (emotionally, physically, socially)
- Imagine certain situations post-mastectomy e.g going swimming, intimacy, bottle feeding
- If they went through surgery and still got cancer, how might they feel?
<table>
<thead>
<tr>
<th>Psychological issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Current/past stresses (biopsychosocial) and impact on emotional wellbeing.</td>
</tr>
<tr>
<td>- What helped them to cope with challenging times? (resilience).</td>
</tr>
<tr>
<td>- Coping strategies.</td>
</tr>
<tr>
<td>- Risk of harm to self of others (past/current).</td>
</tr>
<tr>
<td>- Current/past psychological therapy, medication or other treatment.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Weighing up the pros and cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every decision has two sides... for you, what are the advantages of surgery and what do you think might be the disadvantages?</td>
</tr>
<tr>
<td>Clarify capacity to give informed consent (able to understand and retain information, weigh up pros and cons, communicate their decision).</td>
</tr>
</tbody>
</table>

| Questions – Is there anything else you would like to discuss? Information you feel you need? |
## Feedback, recommendations and next steps

Feedback on assessment, including Questionnaires

### Recommendations:

- Further information gathering/follow-up
- Follow-up with partner
- Contact with support groups
- Psychological/other support
- Macmillan risk-reducing mastectomy booklet
- Other:

- Give info on what happens next e.g. MDT discussion, report, appointment with surgeon

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*I confirm that the above plan has been discussed and verbal consent has been given to proceed.*

<table>
<thead>
<tr>
<th>Name</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>
Appendix 5.
BPS Demonstrating quality and outcomes checklist

Safe
- All clinical staff appropriately registered/accredited.
- All clinical staff receive regular clinical supervision in line with professional guidance.
- All clinical staff undertake CPD in line with professional guidance.
- Clear procedures for governance of risk.
- Service performs audit relating to safety or risk.
- Clinical activity levels are within locally agreed range.
- Demonstration of commitment to evidence-based practice.

Equitable
- Data on age, sex, ethnicity, cancer type and stage, level of distress, case complexity, etc. is captured on each referral.
- Data is analysed and reported regularly.
- Data from referrals is compared to data from the cancer service, local cancer registry and local population.
- Unequal take-up or unmet need is identified and considered.

Responsive
- Service meeting in-patient response targets.
- Service meeting out-patient response targets.
- Service monitors did not attend (DNA) rates.

Patient-centred
- Regular patient experience survey, with plans to address any issues raised.
- Patients offered a flexible choice of appointment times.
- Service accepts self-referrals.
- Use of therapeutic relationship patient-reported questionnaires (PROMs).

Effective
- Locally agreed PROMs.
- Service collects and reports PROMs.
- Illustrates effective impact with case studies of direct and indirect work.

Efficient
- Service always provides feedback to cancer clinicians and GPs.
- Service gathers and report outcomes of Level 2 training.
- Service gathers and report outcomes of Level 2 supervision.
- Illustrates efficient working with case studies of direct and indirect work.

Appendix 6: Example decision tool: Breast cancer reconstruction after surgery for cancer – options

http://optiongrid.org/option-grids/grid-landing/52
# Breast reconstruction after surgery for cancer: options

Use this decision aid to help you and your healthcare professional talk about whether you should have breast reconstruction following your mastectomy.

<table>
<thead>
<tr>
<th>Frequently Asked Questions</th>
<th>No reconstruction (mastectomy only)</th>
<th>Immediate reconstruction</th>
<th>Delayed reconstruction</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is done?</strong></td>
<td>The whole breast is removed, leaving a flat chest wall. You will be given a temporary prosthesis before going home, and a permanent one 6 to 8 weeks later.</td>
<td>The whole breast is removed and a new breast shape is created, using implants or your own tissue. This is done in one operation.</td>
<td>In the first operation, the whole breast is removed, leaving a flat chest wall. In another procedure, sometimes later, a new breast shape is created.</td>
</tr>
<tr>
<td><strong>Will reconstruction make it more difficult to tell if the cancer has come back in the breast?</strong></td>
<td>Does not apply</td>
<td>No. Examination of the reconstructed breast can detect changes. Mammography is not usually done.</td>
<td>No. Examination of the reconstructed breast can detect changes. Mammography is not usually done.</td>
</tr>
<tr>
<td><strong>How likely is it the cancer will come back in the breast?</strong></td>
<td>In about 5 in every 100 women (5%) in the 10 years after mastectomy.</td>
<td>In about 5 in every 100 women (5%) in the 10 years after mastectomy.</td>
<td>In about 5 in every 100 women (5%) in the 10 years after mastectomy.</td>
</tr>
<tr>
<td><strong>What are the common problems?</strong></td>
<td>Tiredness, slow wound healing, itchy scar, and skin breakdown.</td>
<td>Tiredness, slow wound healing, itchy scar, and skin breakdown. Up to 20 in every 100 women (20%) may be unhappy with size and shape and will need further surgery to get both breasts to look the same.</td>
<td>Tiredness, slow wound healing, itchy scar, and skin breakdown. Up to 20 in every 100 women (20%) may be unhappy with size and shape and will need further surgery to get both breasts to look the same.</td>
</tr>
<tr>
<td><strong>What happens to the part where muscle tissue is taken for reconstruction?</strong></td>
<td>Does not apply</td>
<td>You will have a scar where the muscle tissue is removed. It is unlikely that any resulting weakness will limit your usual activities.</td>
<td>You will have a scar where the muscle tissue is removed. It is unlikely that any resulting weakness will limit your usual activities.</td>
</tr>
<tr>
<td><strong>Will a reconstruction delay my other treatments?</strong></td>
<td>Does not apply</td>
<td>Possibly, as your wounds need to heal first. This delay does not mean cancer treatments are less effective.</td>
<td>No. You are given other treatments before the reconstruction.</td>
</tr>
<tr>
<td><strong>How long will it take to get back to usual activities?</strong></td>
<td>Roughly 4 weeks</td>
<td>Up to 3 to 6 months, depending on the type of reconstruction</td>
<td>Up to 3 to 6 months, depending on the type of reconstruction</td>
</tr>
<tr>
<td><strong>Will the nipple be gone?</strong></td>
<td>Yes</td>
<td>It may be possible to keep the nipple or do nipple reconstruction later.</td>
<td>Nipple reconstruction can be done later.</td>
</tr>
<tr>
<td><strong>What will it feel like?</strong></td>
<td>About 10 in every 100 women (10%) feel some tightness or tenderness in the breast area.</td>
<td>The ability to sense touch may be changed; 70 in every 100 women (70%) say that the new breast feels like a part of the body.</td>
<td>The ability to sense touch may be changed; 80 in every 100 women (80%) say that the new breast feels like a part of the body.</td>
</tr>
</tbody>
</table>

*Under Revision: June 2016*

Editors: Carrie Flannagan (Lead Editor), Stuart McIntosh, Cathy McDaid, Heather Emersoon, Alexander Leaper, Samantha Sloane, Marie-Anne Durand, Glyn Elwyn
Editors have declared no conflicts of interest.


This Option Grid® decision aid does not constitute medical advice, diagnosis, or treatment. See Terms of Use and Privacy Policy or www.optiongrid.org
Dear NAME,

**Plan:**

1. **Follow-up with SURGEON**
2. **No further breast care psychology sessions planned. Option for additional support as required.**

It was good to meet you and your husband for an initial psychology appointment on XXX to discuss your thoughts about having risk-reducing breast surgery. This is a summary of our session together which we agreed I would share with your breast surgeon, specialist nurse, and GP.

**Physical health background and your reason for considering risk-reducing surgery**
You told me about your family history of cancer and how the risk of you getting cancer has always been in the back of your mind. You described learning that you hold the BRCA 1 gene mutation as both a shock and almost a confirmation of what you had previously imagined would be the result. You had a long discussion with the genetic counsellors who explained your increased risk of developing breast cancer and some of the options, including surgery and medication, for significantly reducing this risk.

**Surgery: Your understanding, hopes, and expectations of this**
You have been weighing up the two options recommended to you for reconstruction, and have decided to have a DIEP reconstruction as you understand this will lead to a more natural looking outcome and you also feel more comfortable about using your own body tissue. In addition, you said being able to get back to your hobbies (e.g. tennis) was particularly important to you.

I felt you had taken on board a lot of information about surgery and seemed realistic about the likely outcome, including regarding scarring, and reduced breast sensation. You have been advised you will need to reduce your BMI to under 30 and have recently joined Slimming World to help you lose weight. We talked about factors that may help you prepare for surgery and factors that may help you to adjust to your new breasts. You also feel it would be useful to talk to others about what helped them get used to their new breasts and I have given you the contact details of our local support group and the Breast Cancer Care ‘Someone like me’ service, which I hope you find helpful.
Family and social support
You described your husband as very supportive. You have found it helpful to talk through the surgery and some of your worries openly with him and feel more re-assured that you can manage these well together. You have also spoken about who else can help out at home, and with SON, when you have the procedure and during initial weeks following this.

Your emotional wellbeing
We talked about the demands of juggling work alongside being a mum, and how this can naturally feel stressful at times. However, you aren’t feeling especially low or anxious and it seemed to me that you have some good coping strategies in place (e.g. your weekly yoga class), as well as a supportive circle of friends. You have generally valued your breasts as a part of you, and feel some sadness about having surgery to remove them. We spoke about possible ways of ‘saying goodbye’ to them and what practical things you can do to welcome your new breasts as part of you. We also spoke about how if you needed any additional support after surgery with building body confidence we could arrange a review session together.

Summary and recommendations
I felt you were able to talk openly about potential surgery and have been proactive in the way you have been gathering information and making plans for surgery and your recovery with support from your husband. You understand that surgery would reduce your risk of developing breast cancer significantly, though not completely, and seemed very able to weigh up the pros and cons of various options the surgeons have discussed with you to come to an informed decision. You are aware that you will need to lose some weight as part of preparing for surgery and have made a positive start with this. We agreed that the next step is for you to see the plastic surgeon again when you have reached your target weight. We haven’t arranged any further sessions together, but if you would like any further support in the future (either before or after surgery) then please don’t hesitate to contact me.

Best wishes,

Psychologist name, role, team

Copies to:
- Referrer
- Breast surgeon
- Plastic surgeon (if applicable)
- Specialist Breast Nurse
Appendix 7ii. Sample psychology report (example 2)

Dear NAME,

Plan: 1. Delay surgery so you can focus on completing your bereavement counselling and talk to others with personal experience of the procedure.
2. See SURGEON again to discuss the likely cosmetic outcome of surgery and go through your questions about the procedure/recovery period.
3. Review with breast care psychologist in 3 months’ time.

It was good to meet you for an initial psychology appointment on XXX to discuss your thoughts about having risk-reducing breast surgery. This is a summary of our session together which we agreed I would share with your breast surgeon, specialist nurse, and GP.

Background issues and your reasons for considering risk-reducing surgery
Following your diagnosis of breast cancer on DATE, you had a left sided mastectomy followed by chemotherapy and radiotherapy. You explained that you had wanted a bilateral mastectomy at the time but the breast care team advised you to focus on getting through your cancer treatment and to then review risk-reducing surgery at a later date. Although treatment was challenging, you have made a good recovery from this and described feeling physically fit and well. However, you worry about having to go through the challenges of treatment again and after you were recalled following your last scan you feel your right breast is a ‘ticking time bomb’. In light of this you are very keen to have risk-reducing surgery to remove your right breast.

Surgery: Your understanding and expectations of this
We talked about your understanding of the procedure. You understand you have a 20 per cent risk of breast cancer in your right breast, and that surgery would reduce your risk significantly but not to zero. You explained that following a discussion with SURGEON you are planning on having an implant based reconstruction. You have been so focused on the benefits of surgery that you acknowledged you hadn’t thought about the possibility that there could be complications. When we talked through this you anticipated that you would feel ‘gutted’ if there were any complications and you needed more than one operation, as you have been through so much already. You shared that the appearance of your reconstructed breast would be important to you, and hope that your breasts would be symmetrical and ‘normal looking’. When we explored this further you said this would include being symmetrical and not having visible scaring.
We agreed that there is a lot to take on board when considering surgery. In light of this we spoke about the importance of you having further information on the likely appearance of reconstructed breasts (including seeing photographs, if possible) and the process of surgery and recovery so you have a realistic idea of what to expect and be better able to make a fully informed decision. We talked about the value of sharing this information with your husband or ideally him attending the follow-up consultation with you if possible.

**Family and social support**

You explained that your husband has been very supportive. However, you feel he has been through so much with regards to your breast cancer and you feel you need to make the decision about further surgery yourself. We explored some of your concerns about this and whether involving him more at this stage might indeed help him to prepare for surgery and the recovery period as well. You are going to speak to him about joining your follow up appointment(s) with SURGEON.

We also spoke about the potential value of meeting others who have personal experience of the surgery, through a local support group or through the Breast Cancer Care ‘Someone like me’ service and I have given you contact details for these which I hope you find helpful.

**Your emotional wellbeing**

You also described some feelings of loss around your previous surgery, having felt that your breasts had been ‘the best bit of me’. You also shared that your mother sadly died a few months ago from cancer and you are naturally finding this loss hard to cope with, acknowledging being more withdrawn and anxious over recent months. You described having some thoughts about whether life is worth living, but were clear that you don’t have suicidal thoughts and your family gives you strength. We spoke about how these thoughts and feelings may make it harder to fully focus on various options around surgery, and the value of focusing on the counselling sessions you have recently started and then reviewing your thoughts around surgery in due course. Although you had been keen to proceed with surgery you acknowledged that, on balance, you could benefit from some time to be better prepared for surgery, so you are likely to be satisfied afterwards. We agreed to spend some time in our follow-up session talking about what may help you prepare for surgery and also to adjust to your new breast, which you felt would be helpful in light of some of your concerns.

**Summary and recommendations**

I felt you have clear reasons for wanting to pursue a contralateral risk-reducing mastectomy and have the mental capacity to make this decision. At the same time, we discussed the importance of gathering some additional information about surgery (e.g. regarding likely cosmetic outcome), and the benefits of first completing your bereavement counselling before surgery so that you are in the best possible position to fully weigh up your options as part of making an informed decision and adjusting well afterwards. While you described initially feeling disappointed you said you understood the reasons for these recommendations.

You felt you could benefit from further discussions with SURGEON regarding:

- Possible complications with implant based reconstruction.
- Likely cosmetic outcome and to see some photographs if possible (soon after surgery, following recovery).
- Information regarding options for nipples so you can weigh up the pros and cons.

You are also going to consider:
- Attending our local breast reconstruction support group.
- Speaking to your husband about him joining you at your next appointment.

We agreed to meet again in 3 months’ time to review how you are getting on. Please don’t hesitate to contact me if you would like any support in the meantime.

Best wishes,

Psychologist name, role, team

Copies to:
- Referrer
- Breast surgeon
- Plastic surgeon (if applicable)
- Specialist Breast Nurse