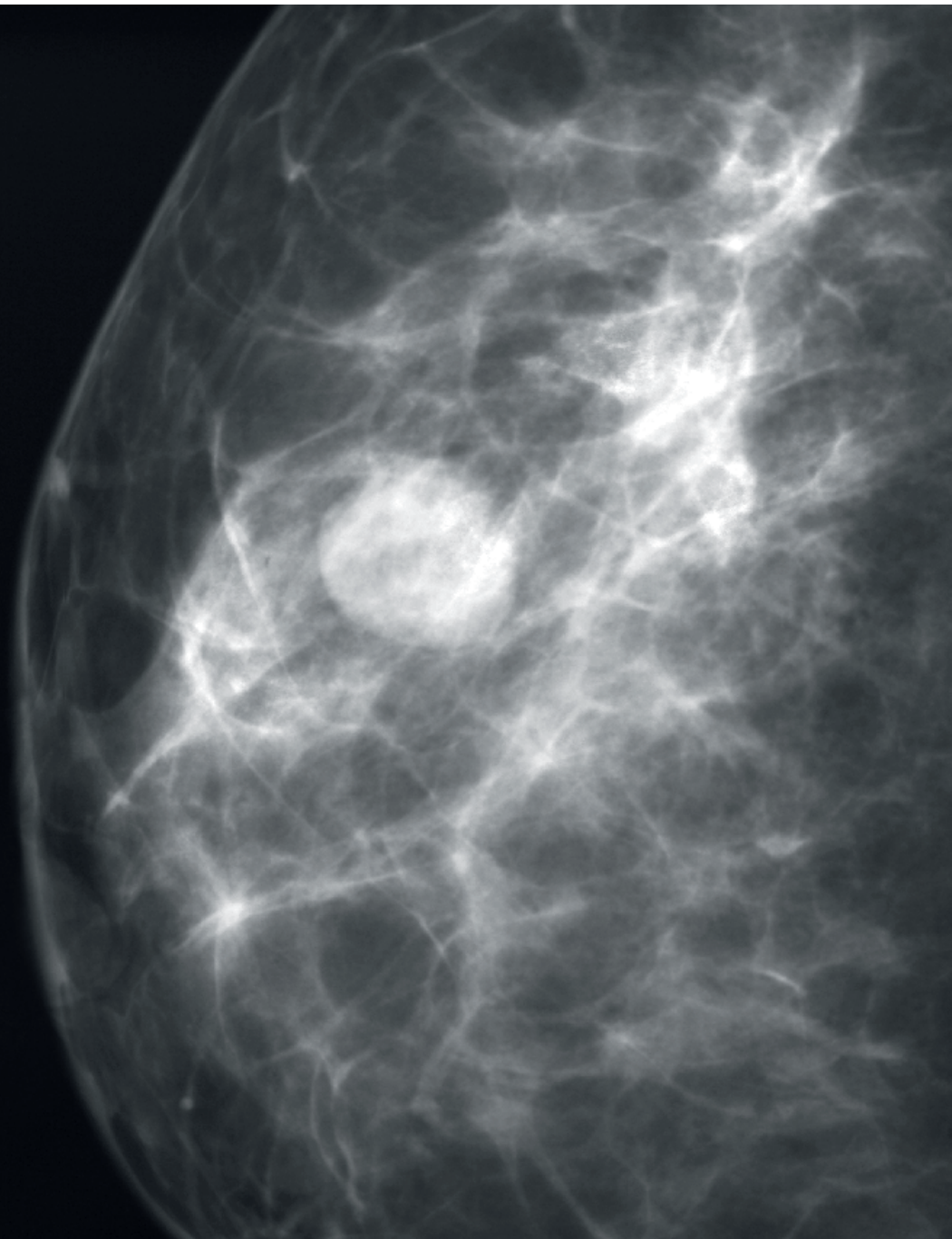


# National Mastectomy and Breast Reconstruction Audit 2011



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**The Royal College of Surgeons of England** is an independent professional body committed to enabling surgeons to achieve and maintain the highest standards of surgical practice and patient care. As part of this it supports audit and the evaluation of clinical effectiveness for surgery.



**The Association of Breast Surgery (ABS) at The British Association of Surgical Oncology (BASO)** is the specialty society that represents breast cancer surgeons and is part of the British Association of Surgical Oncology. It is one of the key stakeholders leading the Audit.



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**The Healthcare Quality Improvement Partnership (HQIP)** promotes quality in healthcare. HQIP holds commissioning and funding responsibility for the National Mastectomy and Breast Reconstruction Audit and other national clinical audits.

# National Mastectomy and Breast Reconstruction Audit 2011

A national audit of provision  
and outcomes of mastectomy  
and breast reconstruction surgery  
for women in England

Fourth Annual Report 2011



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We would also like to thank the five independent sector corporate teams that provided us with hospital-level activity data for the Audit period.

We would like to thank the members of the Clinical Reference Group (Chair, Dick Rainsbury) for overseeing the delivery of the Audit and providing clinical guidance as well as the members of the Project Board (Chair, Julie Henderson) for providing project governance. A list of members of the Clinical Reference Group and Project Board is included in [Appendix 2](#).

We would finally like to acknowledge the contribution of the CASU Helpdesk.

# Forewords

This fourth and final report of the National Mastectomy and Breast Reconstruction Audit represents a major milestone in the history of a truly extraordinary project. The Audit has generated a unique database which sheds new light on key aspects of clinical practice.

The project is the product of 10 years of inter-specialty collaboration, vision, planning and design. It demonstrates just what can be achieved by the NHS when there is widespread support across the country. The extraordinarily high levels of engagement of patients and their clinical teams throughout the Audit are a credit to the many individuals and organisations that have supported the project.

Contained within this final report are some important new findings which will change the information we provide for patients. For the first time, we have evidence from thousands of women which confirms the positive effects of breast reconstruction on their quality of life. Important new data also shows the impact of different reconstructive techniques as well as the timing of surgery on the physical and psychological well-being of our patients. Comparisons between hospitals are reassuring, although they must be interpreted with caution. Nevertheless, the top-performing hospitals are exemplars of just what can be achieved.

Although the rates of breast reconstruction have increased in the UK, this Audit has shown that access to this type of surgery varies enormously across the country. The quality and availability of pre-operative information must be improved to enable women to understand the physical impact of surgery. Surgeons and their clinical teams need to support and help their patients make these often difficult choices. And although most women are very satisfied with their clinical care, this Audit has found complication rates and levels of post operative pain which are much higher than expected. Much remains to be done to ensure that the findings of this Audit drive up the standards of breast reconstruction right across the UK. This unique exercise will not only inform new clinical guidelines, but it will also provide a catalyst for the research and development of more efficient methods of data collection. My thanks goes to all those who have made this remarkable achievement possible.

## Dick Rainsbury

President, Association of Breast Surgery



It is rare to have the opportunity to comment on such a thorough and valuable reflection on the service provided for sufferers of such a major condition as breast cancer. The impact of this disease is well known, but the experience of care offered and delivered has hitherto been anecdotal and grossly skewed in reporting by the preconceptions of involved professionals. The National Audit is therefore of great importance in turning the focus of attention of service providers to what matters most in care – namely the patient's experience and outcome, measured as best can be. The value of patient reported outcomes and experience has been increasingly recognised by not only clinicians attempting to deliver best care, but also by those responsible for service delivery (and funding) – seeking best value for money as well as excellence in outcome.

The Audit has from the outset used the highest standard of methodology and analysis available. The Breast Q instrument, along with well chosen supplementary questions, has delivered reproducible and valid data which can be used for a variety of purposes. 'Benchmarking' of care across the nation, as well as internationally, is possible using such robust methods, and the power of this data should not be underestimated. This audit represents the first time such a cohort has been studied so extensively, and is to be celebrated for the vision of its founders, as well as the degree of interdisciplinary cooperation that it now reflects. The Breast Surgical community (from general and plastic surgical backgrounds alike) has demonstrated the value of shared goals and the satisfaction of learning the true nature of what matters most to patients under their care. Would that such a process were now to be adopted by many other areas of healthcare which are still beset by professional prejudice, unsubstantiated opinion, and futile 'turf wars'. Breast Surgery is leading the way into new working patterns between colleagues, and I am convinced that this will continue, to the inevitable benefit of the patient groups it serves. There are still matters of concern in this report. Perhaps the greatest is the unfortunate fact that only 58 per cent of those eligible for consent to participate were actually entered into the patient-reported outcomes study.

The gauntlet of better care is now well and truly thrown down. It remains for individual units and teams to reflect on this new benchmark of care, to look at how training is delivered to drive up the best standards of care – and in particular the complex but demonstrably superior microsurgically transferred flap reconstructions. The drive for yet better techniques continues; this report could not address some of the novel flaps being developed from sites other than the back or abdomen. The task ahead remains to determine best practice overall, and to ensure that appropriate breast reconstruction options are offered to all women in all hospitals. BAPRAS is wholeheartedly committed to this continuing process of researching, developing, and delivering the best care conceivable to ameliorate the ravages of this profoundly distressing disease. This report is welcome and highly commended.

**Tim Goodacre**

President, British Association of Plastic,  
Reconstructive and Aesthetic Surgeons (BAPRAS)



This fourth and final report contains rich and important information for breast specialist nurses. Not only do we have clear evidence that women need the supportive care of a knowledgeable and skilled nurse at all stages of their care pathway but we now have data that will enable nurses to help women make informed choices with regards to the treatment options available to them.

The report clearly demonstrates that, for many women choosing reconstruction, they will experience improved psychological, emotional and physical outcomes and the data also provides us with a benchmark particularly with regards to longer term outcomes of surgery.

**Maria Noblet**

Chair RCN Cancer and Breast Nursing Forum



This overview of patient experience in the area of cancer related breast surgery will be a valuable tool, both for women making choices at what is often a distressing time, and also for the surgeons and other medical staff who advise and treat them. It is the first evaluation of the benefits or pitfalls of mastectomy, with or without reconstruction, seen from a patient's viewpoint, and as such will be extremely helpful to women comparing the different procedures.

As a former patient (I had a mastectomy with immediate free flap reconstruction in 2002) and as a volunteer for Breast Cancer Care, I have met many women undergoing mastectomies and reconstructions, and have noticed that the quality of their experience can vary widely depending on the hospital that treated them or the medical team that informed them of their reconstructive options. Often I have heard women complain that they have undergone a mastectomy without reconstruction because they were not offered reconstructive surgery or were told that it was not available in their area. This has been borne out by the results of this audit. Hopefully there will now be an increased awareness of the importance of providing enough information on the various options to women at the time of diagnosis, along with access to whichever type of reconstructive procedure they might choose, regardless of whether it is available in their local hospital.

There is much to celebrate in this audit too, particularly the number of women who are very satisfied with their overall care and the excellent treatment that some centres are obviously providing. We can build on this and learn where things are being done well and where there may be areas for improvement, and ensure that women get the best possible experience at what is an emotionally and physically draining time in their lives.

**Christianne Forrest**

Patient Representative  
Breast Cancer Voices



# Executive summary

This is the Fourth and final Annual Report of the National Mastectomy and Breast Reconstruction Audit. The Audit aimed to describe the provision of mastectomy and breast reconstruction services across England, and investigate the determinants and outcomes of care for women with breast cancer having a mastectomy with or without breast reconstruction.

Mastectomy (removal of all breast tissue) is a treatment undergone by many women with breast cancer. The breast mound may be reconstructed at the time of mastectomy (immediate reconstruction) or at a later date (delayed reconstruction). In 2002, the National Institute for Health and Clinical Excellence (NICE) published guidance on improving breast cancer outcomes, and recommended that "reconstruction should be available [to all women with breast cancer] at the initial surgical operation." In February 2009, towards the end of the Audit's data collection period, NICE published revised guidance and re-emphasised the importance of reconstruction after mastectomy:

- [Clinicians should] discuss immediate breast reconstruction with all patients who are being advised to have a mastectomy, and offer it except where significant comorbidity or (the need for) adjuvant therapy may preclude this option.
- All appropriate breast reconstruction options should be offered and discussed with patients, irrespective of whether they are all available locally.

This report provides information on outcomes of mastectomy and breast reconstruction surgery performed between 1 January 2008 and 31 March 2009. The report uses clinician-reported data about the women's condition and their treatment while admitted to hospital. The report also uses patient-reported data on women's experience of care at 3 months after surgery, and patient-reported data on quality of life at 18 months after surgery.

## Audit participation

Overall participation in the Audit was excellent. Data were submitted by all 150 NHS acute trusts in England that provide mastectomy and breast reconstruction surgery. Data were also submitted by 114 independent sector hospitals and six NHS trusts in Wales and Scotland. In total, 18,216 women had complete information entered about their mastectomy or breast reconstruction surgery. During the Audit period, 16,485 women underwent mastectomy. Of these women, 3,389 (21 per cent) had a concurrent immediate reconstruction. The remaining 1,731 women underwent a delayed breast reconstruction.

Engagement with the patient-reported outcomes component of the Audit was variable among participating NHS trusts and independent hospitals. 8,159 women were sent a questionnaire 3 months after their surgery, of whom 6,882 (84.3 per cent) responded. A total of 8,536 women were sent an 18 month questionnaire, slightly more than at 3 months due to late consenting. Of these, 7,110 (83.3 per cent) women returned a completed 18 month questionnaire.

## Information given to women before their surgery

In the 3 month questionnaire, women were asked about how much information they were given before their surgery. Overall, nine out of ten women felt that they had received the right amount of information about their chosen type of procedure (mastectomy, mastectomy with immediate reconstruction, delayed reconstruction).

Women answered a series of questions about their satisfaction with particular aspects of information provision. The majority were satisfied with the information on their surgical procedure (how it was performed, recovery time, and possible complications). Around one-half of women were very satisfied with the information they received on how much pain to expect during recovery, how long it would take "to feel normal again" and what their scars would look like and what postoperative pain to expect.

The responses to the questions combine to form a scale ranging from 0 (low satisfaction) to 100 (high satisfaction). The national average on this scale was 72. The mean scores for many organisations ranged between 60 and 80 but the differences were likely to be due to random variation. A few organisations achieved a mean score above 80, which suggests that this value could be a realistic target for improvement.

## Overall rating of experience and satisfaction with care

The overall experience of care for women with mastectomy and breast reconstruction was excellent. 88 per cent of patients felt that they had always been treated with respect and dignity while in hospital, and 90 per cent of women rated the care they received as excellent or very good.

## Satisfaction with clinicians

Women answered a series of questions about their satisfaction with their consultant and clinical team. The responses to the questions again formed a scale ranging from 0 (low satisfaction) to 100 (high satisfaction). The overall scores on the scales for satisfaction with their consultant and clinical team were very high, being 89 and 91, respectively. Over 90 per cent of women were very satisfied with the competence of their consultant surgeon, and 85 per cent were very satisfied with the professionalism of the team.

Levels of satisfaction with their consultant surgeon and clinical team were typically high across individual organisations. Several organisations had average scores that fell between 70 and 80, which were comparatively low. A realistic benchmark for organisations on this scale could be a score of 90.

## National patient-reported outcomes at 18 months after surgery

The 18 month questionnaire completed by women asked about the results of their breast surgery procedure. Women reported on their satisfaction with the appearance of the breast area, as well as their physical, emotional and sexual well-being.

Figures are provided separately for women who had a mastectomy only, mastectomy with immediate breast reconstruction, or a delayed reconstruction. They should not be interpreted as indicating the relative effectiveness of the various procedures. Each procedure is associated with distinct and different treatment pathways. The choice of operation is likely to reflect women's views, values and expectations. This means that the three groups of women may not be similar. In addition, there is a fundamental difference between immediate and delayed reconstruction in terms of a woman's reference point. Immediate reconstruction patients can only compare their reconstructed breast mound to their breast prior to mastectomy, while delayed reconstruction patients have the additional experience of having been without their breast following mastectomy.

For women having mastectomy only:

- 83 per cent were satisfied with how they looked in the mirror clothed, while 42 per cent were satisfied with how they looked in the mirror unclothed
- Over 75 per cent reported feeling confident in a social setting and emotionally healthy most or all of the time
- 10 per cent reported tenderness in the breast area, and 12 per cent reported arm pain most or all of the time
- 41 per cent reported being satisfied with their sex-life most or all of the time.

For women having immediate breast reconstruction:

- 90 per cent were satisfied with how they looked in the mirror clothed, while 59 per cent were satisfied with how they looked in the mirror unclothed
- 85 per cent reported feeling confident in a social setting and 78 per cent reported feeling emotionally healthy most or all of the time
- 7 per cent reported tenderness in the breast area, and 8 per cent reported arm pain most or all of the time
- 52 per cent reported being satisfied with their sex-life most or all of the time.

For women having a delayed breast reconstruction:

- 93 per cent were satisfied with how they looked in the mirror clothed, while 76 per cent were satisfied with how they looked in the mirror unclothed
- 92 per cent reported feeling confident in a social setting and 88 per cent reported feeling emotionally healthy most or all of the time
- 4 per cent reported tenderness in the breast area, and 9 per cent reported arm pain most or all of the time
- 60 per cent reported being satisfied with their sex-life most or all of the time.

Women's satisfaction with breast area appearance varied by the type of reconstruction for both immediate and delayed reconstruction. Case-mix adjusted outcomes reported by women following a more complex procedure (free flap or pedicle flap reconstruction) were better than those reported by women with an implant-only reconstruction. This highlights the importance of ensuring that women in both the immediate and delayed reconstruction settings are provided with sufficient information and choices about the full range of reconstructive options. Nonetheless, the differences between these groups of women should be interpreted with caution. Women who had a delayed breast reconstruction have lived without a breast/breast mound for a period of time, and consequently, have a different point of reference. They are also a self-selecting subgroup of mastectomy patients with significant interest in cosmetic results.

These individual questions formed scales for satisfaction with breast area appearance, physical, emotional and sexual well-being, with values ranging from 0 (low satisfaction) to 100 (high satisfaction). The overall mean scores for breast area appearance, physical, emotional and sexual well-being, respectively, were 59, 74, 66, and 45. The levels of satisfaction across individual organisations did not differ from these overall mean scores by statistically significant amounts, once patient characteristics and their treatment patterns were taken into account. Mean organisational scores of satisfaction with breast area appearance, physical, emotional and sexual well-being typically differed by an amount that would be expected from random variation.

### Implications for clinical practice

The results of this Audit have shown that the overall experience of care for women undergoing mastectomy and breast reconstruction in England was very good. It is the first time that national data has demonstrated the positive effect of breast reconstruction on quality of life following mastectomy. Women diagnosed with breast cancer should be informed of these findings, and clinicians should ensure that they are supported in making an informed decision about whether or not to have breast reconstruction surgery. The results should also be used to inform women undergoing mastectomy of the likely outcomes of the different types of reconstruction, and what to expect when undergoing these procedures.

Finally, clinicians should address the specific issues raised such as ensuring that women undergoing mastectomy are able to meet their consultants when required to discuss both difficult decisions about the risks and benefits of complex procedures, and long term issues that may arise as a result of their breast cancer surgery and ancillary treatments.

We would like to thank all those organisations who participated in the Audit for their support and effort. The high-level of case ascertainment they achieved has enabled us to provide figures against which practice can be now benchmarked. Hospitals should review the key findings, identify any areas in which local improvements are required, and act to improve the outcomes of surgery in this group of women.

# Recommendations

## Informing and counselling women

1. NHS trusts and independent hospitals should act to maintain the current high levels of satisfaction with both consultant surgeons and breast cancer teams.
2. NHS trusts and independent hospitals should ensure that women are able to be involved in decision making to the degree that they wish, and that staff are available to address the concerns of women undergoing cancer treatments and complex reconstructive procedures.
3. Clinicians should use the summary of the experiences of women undergoing breast reconstruction collected during the Audit to augment information about outcomes obtained from volunteers whose background, cancer treatments and age may differ significantly from the woman making reconstructive decisions.
4. Clinicians should inform women undergoing mastectomy that those who underwent breast reconstruction reported higher levels of emotional and sexual well being than those who underwent mastectomy alone.
5. NHS trusts and independent hospitals should act to ensure that women in both the immediate and delayed reconstruction settings are provided with sufficient information and choices about the full range of reconstructive options.

## Continuing to achieve high quality outcomes

6. NHS trusts and independent hospitals should ensure that they continue to attain the excellent results of mastectomy and breast reconstruction surgery reported by patients.
7. The Audit findings represent the first national data of their type, and should be used by NHS trusts and hospital organisations to define a performance benchmark against which their future outcomes may be compared.
8. Those involved in the development of future guidelines on mastectomy and breast reconstruction should refer to the results of high achieving organisations when setting benchmarks for future audit.

# 1. Introduction

## 1.1 Overview of the Audit

The National Mastectomy and Breast Reconstruction Audit began on 1 January 2007. The principal aims of the Audit were to describe the provision of breast reconstruction services across England, and to investigate the determinants and outcomes of care for women with breast cancer having a mastectomy with or without breast reconstruction.

This is the Fourth and final Annual Report of the Audit. It provides information on mastectomies and breast reconstructions performed between January 2008 and March 2009 using two sources: clinician-reported data about patient characteristics, treatment and inpatient complications; and patient-reported data about the experience of care, post-discharge complications and treatments, and quality of life outcomes.

Breast reconstruction is a safe option for most women undergoing mastectomy.<sup>1</sup> In 2002, the National Institute for Health and Clinical Excellence (NICE) recommended that "reconstruction should be available [to all women with breast cancer] at the initial surgical operation."<sup>2</sup> In February 2009, towards the end of the Audit's primary data collection period, NICE published revised guidance.<sup>3</sup> This re-emphasised the importance of access to breast reconstruction by recommending that:

- [Clinicians should] discuss immediate breast reconstruction with all patients who are being advised to have a mastectomy, and offer it except where significant comorbidity or (the need for) adjuvant therapy may preclude this option.
- All appropriate breast reconstruction options should be offered and discussed with patients, irrespective of whether they are all available locally.

The Audit was originally designed to be a three year project. Its principal component was a prospective study of the care received, and the outcomes attained, by women undergoing mastectomy or reconstruction surgery. The Audit was funded to include women who underwent surgery in England between 1 January 2008 and 30 September 2008. Additional funding enabled the enrolment period to be extended to 31 March 2009 and the collection of long-term (18 month) outcome data from patients.

This Fourth Annual Report includes data on patient experience, information provision and choices. It also contains data on patient quality of life outcomes collected 18 months after surgery. These data are reported nationally and at the individual NHS trust and independent hospital level after appropriate adjustment for patient case-mix and procedure type. The key findings from the Audit's First, Second and Third Annual Reports are summarised in [Appendix 1](#) to provide a background to this report.

## 1.2 Role of mastectomy and breast reconstruction surgery

The incidence of breast cancer has been increasing steadily in England for many years. Between 1977 and 2008, the age-standardised incidence of invasive carcinoma of the breast rose from 75 to 124 per 100,000 women.<sup>4</sup> Ductal carcinoma in situ (DCIS), a non-invasive tumour, is also being detected and treated more frequently following the introduction of the National Health Service (NHS) breast cancer screening programme in 1988. The screening programme and increased breast cancer awareness have also led to more cancers being detected at an earlier stage.

The primary aim of breast cancer treatment is to reduce the risk of premature death by removing or ablating the tumour. Surgery is the first line of treatment for most women, whether or not their tumour is invasive (see Box, page 11). It may involve removal of part (breast conserving surgery) or all (mastectomy) of the breast tissue. Mastectomy may be used when breast conserving surgery would significantly distort the breast shape and contour, when the tumour is multi-focal (in more than one area of the breast), or when most of the breast is involved. Some women, when offered the choice, may also prefer mastectomy to the option of breast conserving surgery. In England, four in ten women diagnosed with breast cancer undergo mastectomy as their primary therapeutic procedure.<sup>5</sup>

A breast reconstruction procedure recreates the breast mound following mastectomy and consequently restores symmetry. Reconstruction can be performed either at the same time as the initial mastectomy (immediate) or at a later date (delayed). Currently, in England and Wales, around 21 per cent of women undergo immediate reconstruction.<sup>6</sup>

There are various approaches to breast reconstruction. One involves the use of an implant under the pectoralis major muscle. These procedures may involve a tissue expander (an implant into which saline may be injected to increase its size) or the insertion of a definitive fixed volume implant.

Reconstruction may also be performed using the patient's own tissue in two distinct ways. 'Pedicule flap' breast reconstruction involves rotating a 'flap', comprised of skin, fat and usually muscle, from the patient's back or abdomen up into the breast area, while keeping intact a tube of tissue containing its blood supply. 'Free flap' breast reconstruction involves a similar flap being completely detached from the patient's body (usually from the abdomen, buttock or thigh) along with its supplying blood vessels. It is then placed at the mastectomy site, where microsurgery is undertaken to restore its blood supply by joining the vessels that supply the flap to vessels in the breast area.

## Overview of surgical treatments for invasive and non-invasive breast cancer

### Invasive disease

For women with invasive disease, surgical management of the tumour may involve breast conserving surgery, mastectomy alone, or mastectomy with immediate or delayed breast reconstruction. Axillary surgery is normally undertaken at the time of the breast conserving or mastectomy procedure.

Axillary surgery involves removal of some or all of the lymph nodes from the axilla (armpit), and is usually performed to determine the prognosis and plan adjuvant therapy. However, extensive axillary surgery may disrupt the drainage of lymphatic fluid from the arm and increase the risk of chronic lymphoedema (swelling). This is particularly a risk for the small number of women who have surgery followed by radiotherapy to the axilla. Sentinel lymph node biopsy involves removing only the first few nodes draining the breast area and is increasingly used to assess spread while minimising this associated risk of lymphoedema.<sup>7</sup>

The likelihood that breast cancer surgery involves mastectomy, mastectomy with immediate reconstruction or breast conserving surgery, depends on factors such as the size of the tumour, its location and its type. These factors also play a role in deciding the types of adjuvant treatments needed. Adjuvant treatments such as radiotherapy may impair the cosmetic results of an immediate breast reconstruction. Immediate reconstruction generally involves a longer wound healing and recovery period than mastectomy alone. It may also delay the administration of radiotherapy and chemotherapy. For these reasons, an anticipated need for such treatments may reduce the likelihood of a woman undergoing mastectomy having immediate reconstruction.

Post-mastectomy radiotherapy to the chest wall, axilla and supraclavicular fossa (area above the collarbone) is given to women at higher risk of cancer recurrence in the breast area. Axillary radiotherapy increases the risk of lymphoedema, but independently reduces the likelihood of local and regional recurrence in those treated.<sup>8</sup> Radiotherapy in the postoperative period may impair the cosmetic outcome of a flap or implant and is seen as a relative contraindication to immediate breast reconstruction.

If indicated, chemotherapy may be given before or after mastectomy. Pre-mastectomy chemotherapy is increasingly used in women with large tumours. It may ensure that a subsequent mastectomy can remove the entire tumour, or even reduce its size to such an extent that breast conserving surgery becomes an option. Chemotherapy reduces the risk of recurrence and death from breast cancer in all age groups.<sup>9</sup>

### Ductal carcinoma in situ

For women with isolated DCIS, surgical management may involve breast conserving surgery, mastectomy alone, or mastectomy with immediate or delayed breast reconstruction. As DCIS may be more extensive and multifocal than invasive disease, a greater proportion of women with isolated DCIS undergo mastectomy even though they have no invasive disease component.

Radiotherapy and hormone therapy are not normally administered to women with non-invasive tumours (eg DCIS) undergoing mastectomy. This reduced need for adjuvant therapies means that they are more likely to be deemed appropriate candidates for immediate breast reconstruction.



Pedicle flaps are frequently used in conjunction with an implant whereas this is very rarely the case for free flap procedures. Thus, there are four main types of reconstruction:

- a tissue expander without the use of autologous tissue
- an implant (or expander) covered by a pedicle flap
- a pedicle flap without the use of an implant or expander
- a free flap.

The likelihood of a woman having a breast reconstruction at the time of her mastectomy depends on many factors, including:

- her personal preferences
- the timing and nature of other treatments for her breast cancer (adjuvant therapies)
- her fitness for reconstructive surgery as determined by factors such as age, general health status, lifestyle and the type of tumour involved
- the type of reconstructive surgery available in the area in which the patient lives.

While there is much uncertainty about the appropriateness of breast reconstruction for certain patients (eg those with other health problems), it is accepted that women should not be prevented from having a breast reconstruction if their hospital does not provide the operation they want. The recent NICE guideline stated that “all appropriate breast reconstruction options should be offered and discussed with patients, irrespective of whether they are all available locally”.<sup>3</sup>

### 1.3 Outcomes of mastectomy and reconstruction

#### Clinical outcomes

Mastectomy and breast reconstruction surgery are comparatively safe procedures. The surgery is elective and this enables a formal, preoperative risk assessment to be performed. Less than 1 in 400 patients die as a result of their surgery<sup>10</sup> and emergency transfer to a high dependency or intensive therapy unit is relatively rare. However, a variety of short-term complications can occur. These include complications related to the removal of breast tissue, the transfer of reconstructive tissue away from a donor site, and the reconstructive procedure itself. Common complications that might occur during the initial admission or after discharge include: wound infection, wound dehiscence (opening of the surgical wound), skin flap necrosis (death of skin adjacent to the wound) or haematoma (the collection of blood between layers of tissue). If serious, these may require medical treatment or reoperation. Other post-discharge problems include persistent pain and numbness in the surgical sites and functional difficulties related to arm and shoulder movement. Treatment of these problems may require readmission to hospital.

The Audit described the rates of inpatient complications that required some form of therapeutic intervention in its Third Annual Report ([see Appendix 1 for an overview](#)).

#### Patient reported outcomes

It is widely accepted that patients can provide a valid and reliable perspective with respect to their care experience and the effectiveness of their treatment.<sup>11</sup> Patients' experience of care is a key dimension of healthcare quality, alongside safety and clinical effectiveness. For patients undergoing mastectomy with or without breast reconstruction, the core elements of a high quality care experience include:

- involvement in treatment decisions
- provision of appropriate information
- provision of appropriate choices and access to care
- safe and effective surgery
- adequate pain control
- satisfaction with the care received from doctors and nurses
- treatment with respect and dignity throughout the episode.

Many dimensions of a woman's quality of life can be affected by breast cancer surgery including body image, self-esteem, confidence, sex life, physical pain, activities of daily living and social life. An aim of the Audit is to investigate the impact of mastectomy and breast reconstruction on quality of life. Information on these outcomes is included in chapters 6 and 7 of this report.

## 2. Patient reported outcomes: methods and participation rates

### 2.1 Audit methodology

All NHS acute trusts and independent sector hospitals that provide mastectomy and breast reconstruction surgery in England were invited to participate in the prospective audit of practice and outcomes. Hospitals were asked to enrol all women, aged 16 years and over, diagnosed with breast cancer or DCIS who underwent unilateral mastectomy or primary breast reconstruction between 1 January 2008 and 31 March 2009. Data collection was required from both the local staff treating the patient and the patient herself.

#### Data collected by hospital staff

The dataset collected by local hospital staff was split into five sections. The first section recorded patients' demographics and their willingness to receive follow-up questionnaires at their home address. Subsequent sections recorded information about the type of operation and the reconstructive choices made available, previous treatments and comorbidity, tumour characteristics, and complications before discharge. Sample clinical datasheets can be viewed on the Audit website at: [www.ic.nhs.uk/mbr](http://www.ic.nhs.uk/mbr)

#### Data collected from patients

Women who consented to complete the Audit's patient-reported outcome measures were asked to complete questionnaires at 3 and 18 months after surgery. Both were administered in the same way. At the appropriate time, women were posted the questionnaire and were asked to complete and return it in the supplied prepaid envelope. If the questionnaire was not received after 5 weeks, participants were sent a reminder letter with an additional questionnaire.

The 3 month questionnaire asked about the provision of information, reconstructive choices, pain management, postoperative complications and their overall care experience. Three distinct questionnaires were developed for women undergoing mastectomy, immediate reconstruction and delayed reconstruction due to differences in their treatment pathways.

The 18 month questionnaire covered various dimensions of women's quality of life after surgery. There were two distinct questionnaires, one for women who had undergone mastectomy alone, and the other for women who had undergone immediate or delayed reconstruction. Sample 3 month and 18 month questionnaires can be viewed on the Audit website at: [www.ic.nhs.uk/mbr](http://www.ic.nhs.uk/mbr)

#### Patient-reported satisfaction and outcomes: scales and individual items

The 3 month and 18 month questionnaires used a number of scales specifically developed for use in women undergoing mastectomy and breast reconstruction surgery.<sup>12</sup> These scales related to particular outcomes of care (eg satisfaction with breast area appearance, satisfaction with outcome, emotional (psychosocial) well-being, physical well-being, and

sexual well-being) and consist of a set of related questions or 'items' whose responses are combined to give an overall score. All scales were scored from 0 (minimum) to 100 (maximum).

In this report, we have chosen to provide the overall score of individual scales and the details of the item-level responses (broken down by procedure type). While many studies only report the overall scores, we feel that the item-level responses are important to patients and clinicians, and are provided to help identify specific areas for practice improvement.

#### Statistical analysis

National rates of post-discharge events and outcomes are typically expressed as percentages, being derived either for all women or for women who underwent one of the primary procedures (mastectomy, mastectomy with immediate reconstruction or delayed reconstruction). The statistical significance of differences between percentages was assessed using the chi-squared test. All p-values are two-sided and those lower than 0.05 were considered to indicate a statistically significant result. STATA 10 software was used for all statistical calculations.

Scores reflecting patient satisfaction with information and reconstructive choice, ratings of care experience, and quality of life outcomes following surgery were derived for each NHS trust and independent hospital. We previously reported results of geographical variation, such as rates of immediate reconstruction by Cancer Network.<sup>5,6</sup> This was done because women often undergo immediate reconstruction at specific hospitals within a Network. For this reason, describing reconstructive utilisation at an organisation level would be misleading. This does not apply for the reporting of outcomes. Hospital organisations are responsible for the outcomes attained and the quality of care provided to their patients. It is therefore appropriate to attribute patients' reports of their experience and postoperative quality of life to the NHS trusts and independent hospitals that carried out their surgery.

The mean scores for each organisation were risk adjusted to take into account the patient populations and modes of treatment at different hospitals. Without this risk-adjustment, differences between organisations could reflect differences between patients or other variables over which an organisation has limited control. For the scores related to satisfaction with the process of care (information provision and satisfaction with their surgeon and clinical team), the risk adjustment model assessed the contribution of age, performance status, and level of deprivation as these factors are known to be related to patients' perceptions and expectations. However, only age was found to be associated with the patient responses. For the patient-reported outcomes measured at 18 month, the risk adjustment assessed the contribution of age, performance status, level of deprivation, clinical characteristics and the type of procedure undergone.

Multiple regression models were used to derive the risk-adjusted scores for each healthcare organisation. Women were allocated to the NHS trust or independent hospital that undertook their primary surgery. Multilevel regression models were also developed to examine the influence of clustering. The results of the multilevel models were very similar to the ordinary multiple regression models, and for simplicity, we present the latter in this report.

For each experience and outcome measure, the variation in the mean scores of the hospital organisations was examined using a funnel plot.<sup>13</sup> This plot tests whether the mean score of any single NHS trust or independent hospital differs significantly from the national rate. We used two sets of control (funnel) limits: the inner limits indicate the interval within which 95 per cent of providers would be expected to fall if variation was due only to sampling error (representing a difference of two standard deviations from the national rate). The outer limits correspond to 99.8 per cent (representing a difference of three standard deviations) of mean scores. The control limits were derived using the common standard deviation of the scores across all patients, divided by the square root of the number of patient responses at that provider (labelled provider volume). The sampling distribution of mean scores was assumed to be Normal. Following convention, we used the 99.8 per cent limits to identify “outliers” because it is unlikely for an organisation to be beyond these limits solely because of random variation (a 1 in 500 chance). Funnel plots only include organisations for whom the Audit had values for at least three women.

### The interpretation of outliers

The interpretation of the mean scores for organisations on the patient-reported outcome measures needs to be undertaken cautiously. This is the first time that these scores are presented and there are also no pre-existing standards against which hospitals could have benchmarked themselves. The funnel plots are centred about the overall average and this will influence where the control limits are placed.

The results of participating hospitals are compared to the mean score of the sample population recruited by all participating organisations. The patient-reported outcomes study was not undertaken at 6 NHS trusts and 30 independent hospitals that provided clinical information. A further 95 hospital organisations asked less than 50 per cent of their patients for consent (Appendix 3). This raises the possibility that the reported overall mean scores are not equal to the mean of the true population of women treated across England. There are several reasons why this could arise. First, some of the variation may reflect selection bias due to different levels of consent among participating hospital organisations. Second, the non-participating organisations may be different in systematic ways from those who did participate. For example, a recent study of participation in the National Bowel Cancer Audit suggested that hospital organisations with poor levels of participation had slightly higher mortality rates than those that did.<sup>14</sup> If this finding applied to this Audit, the mean scores on the

patient-reported outcome measures for all women eligible to participate would be slightly lower than the values reported. Consequently, it is possible that this would change the outlier status of hospital organisations with higher or lower than expected scores on specific outcomes, particularly those close to these limits.

In addition, outcomes with respect to emotional, physical and sexual well-being will reflect pre-existing problems and issues in addition to the diagnosis and treatment of a woman’s breast cancer. Comparing outcomes across hospital organisations makes the assumption that there were no significant and systematic differences in women’s preoperative status at different organisations. Information could not be collected on whether this was true because patients were enrolled into the Audit after the diagnosis of breast cancer had been established. Consequently, while risk-adjustment will have corrected for known confounders, the organisational figures may still be influenced by some residual confounding.

### 2.2 NHS trust and independent hospital rates of consent and response

The extent to which patients were successfully recruited to the patient-reported component of the Audit varied across NHS trusts and independent hospitals. Among women with clinical data, 10,632 women (58 per cent) were asked to consent to take part in this element of the Audit. The proportions of eligible women who were asked to consent to take part are given at the NHS trust and independent hospital level in Appendix 3.

In some cases, hospital staff did not ask for consent due to legitimate concerns regarding poor eyesight (n=27), literacy or language comprehension issues (n=166), or cognitive impairment (n=202). However, a large number of women were not approached for this element of the Audit due to logistical problems with consent procedures. No women were asked for consent at 6 English NHS trusts and 30 independent hospitals. This means that, in this report, we only include patient-reported outcomes from a subset of NHS trusts and independent hospitals that chose to participate.

Among those women that were asked, 8,725 (82 per cent) women agreed to participate. Of these women, 7,783 (89 per cent) were being treated at 141 NHS acute trusts in England and 696 (8 per cent) were being treated at 79 independent sector hospitals. The final 246 (3 per cent) women were consented at the six participating non-English NHS trusts.

Delays in registering some patients meant that their 3 month questionnaires could not be sent out on time. A number of consented women also died during or following their admission. After excluding these two groups of women, 8,159 women (93.5 per cent) had a 3 month questionnaire sent to their home address. Of these, 2,580 (31.6 per cent) did not initially respond and were sent a reminder questionnaire after five weeks.



In total, 6,882 (84.3 per cent) women returned a completed 3 month questionnaire. Response rates were similar across the three groups, although a lower proportion of mastectomy patients gave their consent compared to those who underwent reconstruction (Table 2.2).

The delays in registration did not affect the distribution of the 18 month questionnaires. However, after further excluding those women who died in the extended follow up period, 8,536 women (97.8 per cent) had an 18 month questionnaire sent to their home address. Of these, 2,230 (26.1 per cent) did not initially respond and were sent a reminder questionnaire. In total, 7,110 (83.3 per cent) women returned a completed 18 month questionnaire. Response rates were similar across both surgical groups (Table 2.2).

The returned questionnaires typically had all questions completed, and there were no specific concerns about data quality. Some women chose not to answer the set of questions about sexual well being on the 18 month questionnaire, while others indicated that these questions were not applicable to them. Women had the option to "skip" or tick "not applicable" responses if they did not wish to answer a specific question about this topic.

## 2.3 Biases in patient-reported outcomes data

This is the first time that national comparative data on patient-reported experience and outcomes have been collected and reported for breast cancer surgery. The Audit findings must therefore be interpreted cautiously. The findings should be used primarily to inform patients and clinicians about overall outcomes and assist with joint decision-making.

There are a number of reasons for this caution. First, as noted above, the proportion of eligible women asked to participate varied between hospital organisations, introducing a risk of sample bias. Second, patients' recall of events may change over time and this can influence their reporting of outcomes and ratings of patient experience.<sup>11</sup> The Audit tried to keep the distribution of the 3 month and 18 month questionnaires within a narrow period of time around the census point. However, this was not always possible for the 3 month questionnaire.

During the Audit, there were delays in the consent status of patients being recorded in the online database at some organisations. There were additional problems due to delayed linkage with the National Strategic Tracing Service, which was necessary to ensure that patients had not died and to obtain their current address. Finally, five week reminder letters (with enclosed questionnaires) to initial non-respondents increased the interval between surgery and questionnaire completion, although they improved the overall response rate. This last issue is routinely encountered when distributing patient-reported outcome questionnaires and there is no evidence that the outcome scores following a reminder letter differ systematically from those of first time respondents.

**Table 2.1**  
Number of women asked for consent and the proportion that gave consent by surgery type

Patient characteristics	Mastectomy only	Immediate reconstruction	Delayed reconstruction	Overall
Number of women asked for their consent	7,251	2,163	1,107	10,521
Number (%) of women who gave consent when asked	5,713 (79)	1,939 (90)	984 (89)	8,636 (82)

**Table 2.2**  
Number of 3 and 18 month questionnaires sent and the proportion that responded by surgery type

3 month questionnaires	Mastectomy only	Immediate reconstruction	Delayed reconstruction	Overall
Number of women sent a questionnaire	5,418	1,857	884	8,159
Number (%) of those sent a questionnaire who returned it	4,637 (86)	1,553 (84)	692 (78)	6,882 (84)
18 month questionnaires	Post-mastectomy	Post-reconstruction	Overall	
Number of women sent a 18 month questionnaire	5,580	2,956	8,536	
Number (%) of those sent a questionnaire who returned it	4,726 (85)	2,384 (81)	7,110 (83)	

Overall, 67 per cent of the 3 month questionnaires were returned between 3 and 6 months. 90 per cent were returned between 3 and 9 months. We examined whether there was a relationship between the interval of completion and the various patient-reported outcomes (the analysis used 4 categories of response interval: under 3 months, 3 to 6 months, 6 to 9 months and more than 9 months, with differences being tested using the chi-square test). In the majority of cases, there was no statistical association between time interval and an outcome measure. Important exceptions were

1. the level of satisfaction with the quantity of information decreased across the longer response intervals from 92 per cent to 89 per cent.
2. the level of satisfaction among mastectomy-only patients with the quantity of information on reconstruction was slightly higher among women who responded between 3 to 6 months compared to the other intervals.
3. among women who returned the questionnaire 3 to 6 months after surgery, a slightly higher proportion reported that they were always treated with respect, and reported their overall rating of care as excellent or very good.
4. Rates of postoperative complications were not statistically different across the response intervals with the exception of the proportion of women experiencing the collection of fluid requiring drainage. This increased with time.

Although the response interval had a statistically significant effect on some questions, the size of the effect tended to be small. Consequently, we considered that this bias was likely to be less than the bias that might be introduced if the analysis was restricted to only those women who returned their questionnaire between 3 and 6 months. Moreover, the effect of including the data from women with a long response interval tended to reduce the estimated levels of patient experience. Thus, the 3 month patient-reported results may be conservative.

There were fewer difficulties with the timely distribution of the 18 month questionnaires, with over 90 per cent of the 18 month questionnaires being returned between 18 and 20 months of the operation date. As the clinical data collection period was already complete, delays in the consent status of patients being recorded in the online database at some organisations had no effect. The linkage to the National Strategic Tracing Service had already been established. Only the five week reminder letters (with enclosed questionnaires) to non-respondents increased the interval between surgery and questionnaire completion.

## 3. Patient characteristics and patterns of care

### 3.1 Patient characteristics

Of the 18,216 women with complete operative data submitted to the Audit during the 15 month data collection period, 16,485 underwent mastectomy, of whom 3,389 (20.6 per cent) had an immediate reconstruction. The remaining 1,731 women underwent delayed breast reconstruction following a previous mastectomy. The patient characteristics of the sample populations who completed and returned 3 and 18 month questionnaires and reported on their experience and outcomes did not differ significantly from that of the Audit population.

### 3.2 Types of breast reconstruction procedures

Table 3.1 describes the types of immediate and delayed reconstruction procedure performed on women in the Audit. The patient sample that completed and returned 3 and 18 month questionnaires was representative of the Audit population in terms of the procedure types they had undergone. Most immediate reconstruction patients had a reconstruction that involved an implant (with or without a flap), while the majority of delayed reconstruction patients underwent reconstruction using only a flap of their own tissue. Randomised clinical trials have not been undertaken to compare the outcomes of different types of reconstruction. For this reason, there is no evidence to suggest that one type of reconstruction is better than another in terms of quality of life or patient safety. However, differences in the types of reconstruction undergone in the immediate and delayed settings are likely to reflect limited access to some types of reconstruction at the time of mastectomy.<sup>5</sup>

**Table 3.1**  
Type of primary reconstruction among women in the Audit and who returned 3 month and 18 month patient questionnaires

Type of surgery	Immediate Reconstruction N (%)			Delayed Reconstruction N (%)		
	Clinical dataset	3 month	18 month	Clinical dataset	3 month	18 month
Implant/expander-only	1,246 (37)	476 (33)	447 (33)	281 (16)	93 (14)	88 (13)
Pedicle flap + implant/expander	735 (22)	318 (22)	290 (22)	438 (25)	167 (25)	164 (25)
Pedicle flap (autologous)	932 (27)	452 (30)	397 (30)	446 (26)	164 (25)	181 (27)
Free flap	476 (14)	218 (15)	199 (15)	566 (33)	236 (36)	237 (35)
<b>Total</b>	<b>3,389</b>	<b>1,464</b>	<b>1,333</b>	<b>1,731</b>	<b>660</b>	<b>670</b>

## 4. Patient satisfaction with preoperative information

### 4.1 Information on mastectomy and reconstruction procedures at 3 months after surgery

One of the key questions of the Audit was to determine if women undergoing mastectomy are given enough information preoperatively to make an informed decision about breast reconstruction. In 2002, the Improving Outcomes guidance from NICE<sup>2</sup> outlined the standard that clinicians should try to achieve for all breast cancer patients:

“At every stage, patients should be offered clear, objective, full and prompt information in both verbal and written form. Each patient should receive information relevant to her case about the disease, diagnostic procedures, treatment options and effectiveness. The amount and timing of information should take each patient’s preferences into account. When there is a genuine choice between treatments, the information given must be sufficiently clear and detailed to allow the woman to make a decision based on evidence of differences in outcome.”

In the 3 month questionnaire, women were asked about how much information they were given before their operation: not enough, the right amount or too much.

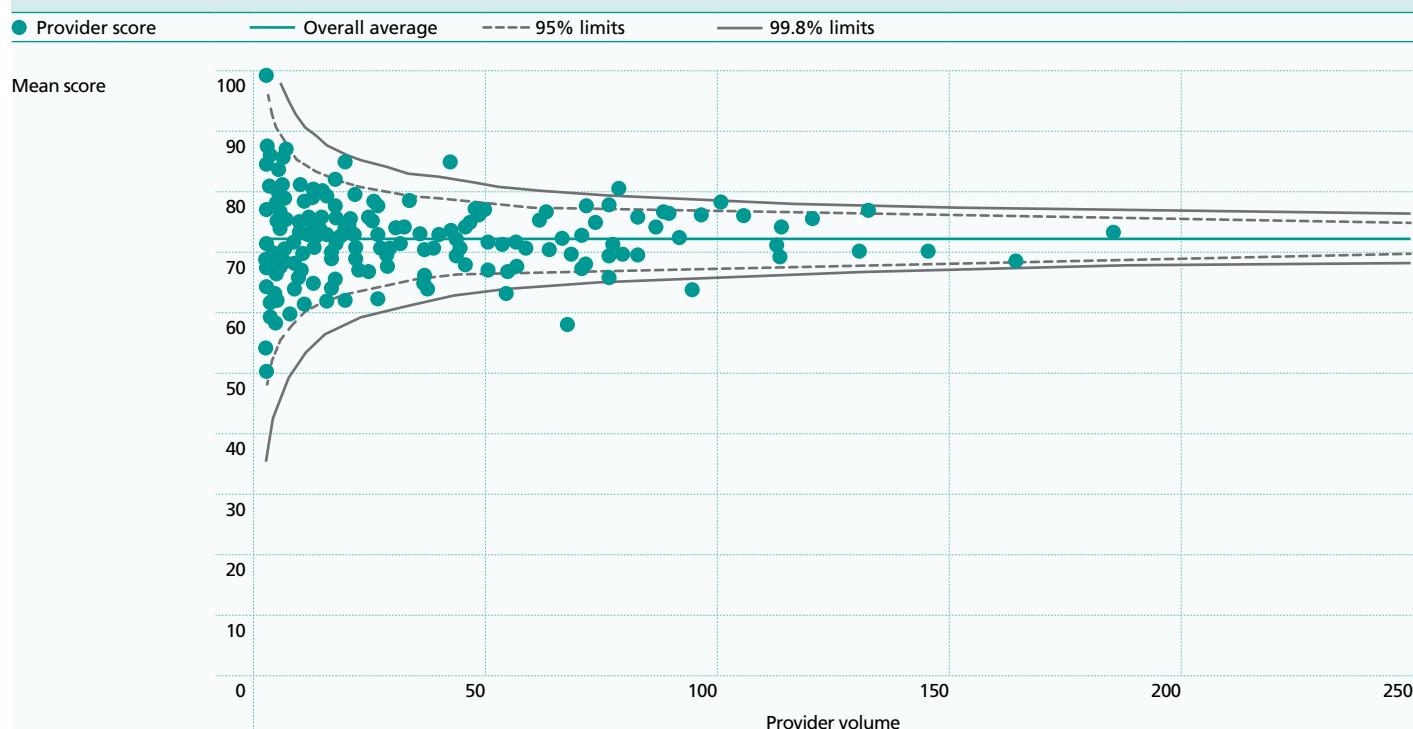
In all three surgical groups, nine out of ten women felt that they had received the right amount of information about their surgery (Table 4.1). This compares very well to how other groups of hospital inpatients rate the provision of information about their treatment. The national inpatient survey collected responses of a sample of all English inpatients treated in 2008 and reported an equivalent figure of 79 per cent. [Question 40]<sup>15</sup>

Women also answered a series of questions about satisfaction with particular aspects of information provision in more detail. The responses to these questions were combined to form a scale for which scores range from 0 (lowest) to 100 (highest satisfaction). The mean score for individual NHS trusts and independent hospitals on this scale is shown in Figure 4.1. The funnel plot compares the adjusted scores for each organisation with the mean score for all responses of 72 (scores were adjusted for women’s age at the time of surgery). The funnel plot highlights that, while the mean scores varied between 60 and 80, the number of responders at many individual hospitals was sufficiently small for random error to possibly contribute substantially to the observed variation. There were four organisations

**Table 4.1**  
Patient views on the quantity of information about surgery provided preoperatively

	Percentage of women who gave each rating		
	Mastectomy only (%)	Immediate Reconstruction (%)	Delayed Reconstruction (%)
Not enough	8	9	8
The right amount	91	89	91
Too much	1	2	1

**Figure 4.1**  
Mean adjusted scores on the satisfaction with information provision scale for NHS trusts and independent hospitals based on patient responses on the 3 month questionnaire



\* Scores adjusted for age of the women at time of surgery

whose adjusted mean score fell below the 99.8 per cent lower control limit, while two organisations whose score was above the upper control limit. We note that a number of organisations had mean scores lower than those of the “low outliers” but these scores were based on only a few responses and the sample size was insufficient to distinguish between true differences in the care provided and variation due to sampling error.

The two organisations whose scores were both above the upper control limit had mean scores above 80. Thus, while a score of 72 could be adopted as a benchmark for organisations, this suggests that a score of 80 could be adopted as an aspirational target.

We would recommend that NHS trusts and independent hospitals examine whether there are local barriers to the effective provision of preoperative information, and whether their overall levels of patient satisfaction with this important aspect of the cancer care pathway can be improved. Table 4.2 gives the proportion of women who were very satisfied with each particular aspect of information provision. There are no set standards for these items at present. However, organisations may use these results to identify areas in which information provision may be improved.

The figures are presented for the three types of surgery together but comparisons should be limited to within each column rather than across the surgical groups. While women in the mastectomy and immediate reconstruction groups were reporting satisfaction with their only clinical team, the figures for those who underwent delayed reconstruction probably represent views of both their current team and that which carried out their mastectomy.

Levels of satisfaction were highest for the information on the surgical procedure: how it was performed, recovery time, and possible complications. Less than 5 per cent of women reported being dissatisfied (somewhat or very) with how

the procedure was performed. Around one-half of women were very satisfied with the information they received on what their scars would look like and what postoperative pain to expect. The area of information with which the lowest proportion of women was very satisfied in all surgery groups was on what other women experience with their surgery, and in those who underwent breast reconstruction how long it would take to ‘feel like yourself’ or ‘feel normal’. Lower levels of satisfaction about what other women experience and how long it would take to feel normal may reflect the lack of information available about these topics rather than a failure to inform patients. We hope that the 18 month patient-reported data collected during the Audit will begin to provide clinicians and patients with some of this information.

There are two other notable aspects of these data. First, women undergoing delayed reconstruction were less satisfied with the information they received about having breast reconstruction at the time of mastectomy or later. Around one third of all women reported being dissatisfied (somewhat or very) on this item.

Second, among immediate and delayed reconstruction patients, women were less satisfied with the information they received about how their surgery would affect breast cancer screening. Around one quarter of all women reported being dissatisfied (somewhat or very) on this item. There are several possible explanations for this. It may be that clinicians did not inform women about these issues until their postoperative follow up. Alternatively, as many of the reconstructions were carried out at plastic surgery units, it may be that their staff members were less likely to discuss these breast cancer management issues than their colleagues within the breast surgery unit. As the figures are comparable for both the immediate and delayed reconstruction patient groups, it is unlikely that there is an issue with the time available to inform women, or women retaining the information following a cancer diagnosis.

**Table 4.2**  
Patient responses on the items forming the “Satisfaction with information provision” scale as reported on the 3 month questionnaire

Information domain	Percentage of women who were very satisfied*		
	Mastectomy only (%)	Immediate Reconstruction (%)	Delayed Reconstruction (%)
How the surgery was to be done	70	79	82
Healing and recovery time	62	61	66
Possible complications	58	61	70
Options regarding types of breast reconstruction	.	71	75
Having a breast reconstruction at the time of mastectomy versus later	.	74	44
How long the process of breast reconstruction would take	.	63	62
What size you could expect your breasts to be	.	63	65
How much pain to expect during recovery	56	54	62
What you could expect your breasts to look like	.	56	62
How long it would take to feel like yourself/feel normal again	.	43	52
How the surgery would affect future breast cancer screening (eg mammograms)	.	40	40
Lack of sensation in your reconstructed breast and nipple	.	50	58
What other women experience with their surgery	39	34	41
What the scars would look like	43	55	58

\* Response options were: very dissatisfied, dissatisfied, satisfied or very satisfied

# 5. Patient reported experience of care at 3 months after surgery

## 5.1 Overall rating of experience and satisfaction with care

The Care Quality Commission (CQC) undertakes an annual survey of patient satisfaction with care across all NHS trusts. The survey questionnaire, designed by the Picker Institute, is freely available and may be used for local and national surveys. We included two questions from the national inpatient survey in the 3 month postoperative questionnaire. The first question asked if women felt they were treated with respect and dignity while they were in hospital. The second asked how they would rate the care they received overall.

The responses to these two questions by women in the Audit are given in [Table 5.1](#), broken down by surgery type. We have also included the results from the national inpatient survey that contained responses from NHS inpatients treated in 2008.[Questions 69, 70]<sup>15</sup> It is encouraging that most women undergoing mastectomy and reconstruction surgery rate the care they have received very highly. Women who underwent mastectomy or breast reconstruction surgery were more likely to feel that they had been treated with respect and dignity while in hospital, and to rate the care they received as excellent or very good compared to the

general population of inpatients. However, these comparative results should be interpreted with caution. The population of all NHS hospital patients treated in 2008 included patients admitted through both the emergency and elective pathways. In addition, our sample includes women treated in the independent sector. These differences mean that the patients enrolled in the two surveys are likely to differ in ways that affected their expectations, and consequently, their responses. We also note that the reconstructive population differs from the population of women who have mastectomy only, for example in terms of age. This is likely to influence the overall ratings for each procedure.

In the 3 month patient questionnaires, women were asked about the care they received from their consultant surgeon ([Table 5.2](#)). The percentage of women very satisfied with their consultant surgeon was very high, with over three-quarters of women being very satisfied on nearly all the domains. The proportion of women who were not satisfied (dissatisfied or very dissatisfied) on any item was typically between 0 and 5 per cent. The exception was the item on whether their consultant surgeon was available when they had concerns, with around 10 per cent of women being not satisfied.

**Table 5.1**  
Overall assessment of treatment at 3 months after surgery

Question	Response	NHS survey (2008) (%)	Mastectomy only (%)	Immediate reconstruction (%)	Delayed reconstruction (%)
Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Yes, always	79	89	86	89
	Yes, sometimes	18	10	13	10
	No	3	1	1	1
Overall, how would you rate the care you received?	Excellent	43	66	72	74
	Very good	35	24	19	17
	Good	14	7	6	7
	Fair	5	2	2	1
	Poor	2	1	1	1

**Table 5.2**  
Levels of satisfaction with consultant surgeon at 3 months after surgery +

Information domain	Percentage of women who were very satisfied *		
	Mastectomy only (%)	Immediate Reconstruction (%)	Delayed Reconstruction (%)
Was competent?	92	96	96
Gave you confidence?	86	91	92
Involved you in the decision-making process?	75	81	87
Was reassuring?	82	87	89
Answered all your questions?	83	87	91
Made you feel comfortable?	83	86	91
Was thorough?	86	90	92
Was easy to talk to?	80	83	88
Understood what you wanted?	79	83	88
Was sensitive?	78	82	86
Made time for your concerns?	76	82	83
Was available when you had concerns?	69	75	76

+ For women who had immediate reconstruction, this was the consultant surgeon responsible for their mastectomy

\* Response options were: very dissatisfied, dissatisfied, satisfied or very satisfied

Also of note is that the item on whether the consultant surgeon “involved [women] in the decision-making process” had a comparatively low rating of satisfaction among women undergoing mastectomy. This may reflect the relative paucity of decision-making opportunities made available to women who undergo mastectomy as a primary cancer treatment. This percentage of women who were very satisfied with their involvement in decision making was also scored lower than other items by women undergoing immediate reconstruction. This may reflect the type and timing of reconstructive options offered in the immediate setting.

Women were further asked about their satisfaction with the other members of the clinical team; namely, the other doctors and nurses that treated them (Table 5.3). As before, the percentage of women who were very satisfied with their clinical team was very high. The proportion of women who were not satisfied (dissatisfied or very dissatisfied) on any item was typically between 2 and 8 per cent. Over three-quarters of women were very satisfied that staff were professional, respectful, friendly and kind, and made them feel comfortable, and were knowledgeable and thorough.

These are very high ratings of satisfaction, and we hope that staff will continue to practice to these standards. To improve their care further, we recommend that hospital organisations ensure that women are able to be involved in decision making to the degree that they wish<sup>16,17</sup>, and that time is available for staff to address the concerns of women undergoing cancer treatments and in some cases complex reconstructive procedures.

Figures 5.1 and 5.2 provide adjusted mean scores for satisfaction with the consultant surgeon and clinical team at individual NHS trusts and independent hospitals. In both funnel plots, the mean score of all responses is used as the comparator, and hospitals’ scores are adjusted for the ages of their patients. The overall mean scores for satisfaction with the consultant surgeon and clinical team were 89 and 91, respectively.

The two figures show that adjusted mean levels of satisfaction with both consultants and the rest of the medical team at individual hospital organisations were mostly within the range expected from random fluctuations alone. Six organisations had an adjusted mean score for consultant satisfaction that was below the 99.8 per cent lower control limit, while two others had scores above the upper control limit. On the scale measuring satisfaction with the clinical team, six organisations had an adjusted value below the lower control limit. However, the overall mean scores on these two measures were very high. Organisations could use a mean score of 90 as a realistic benchmark, and we would recommend that NHS trusts and independent hospitals continue to ensure that the high levels of satisfaction with their consultants and their breast cancer teams are maintained.

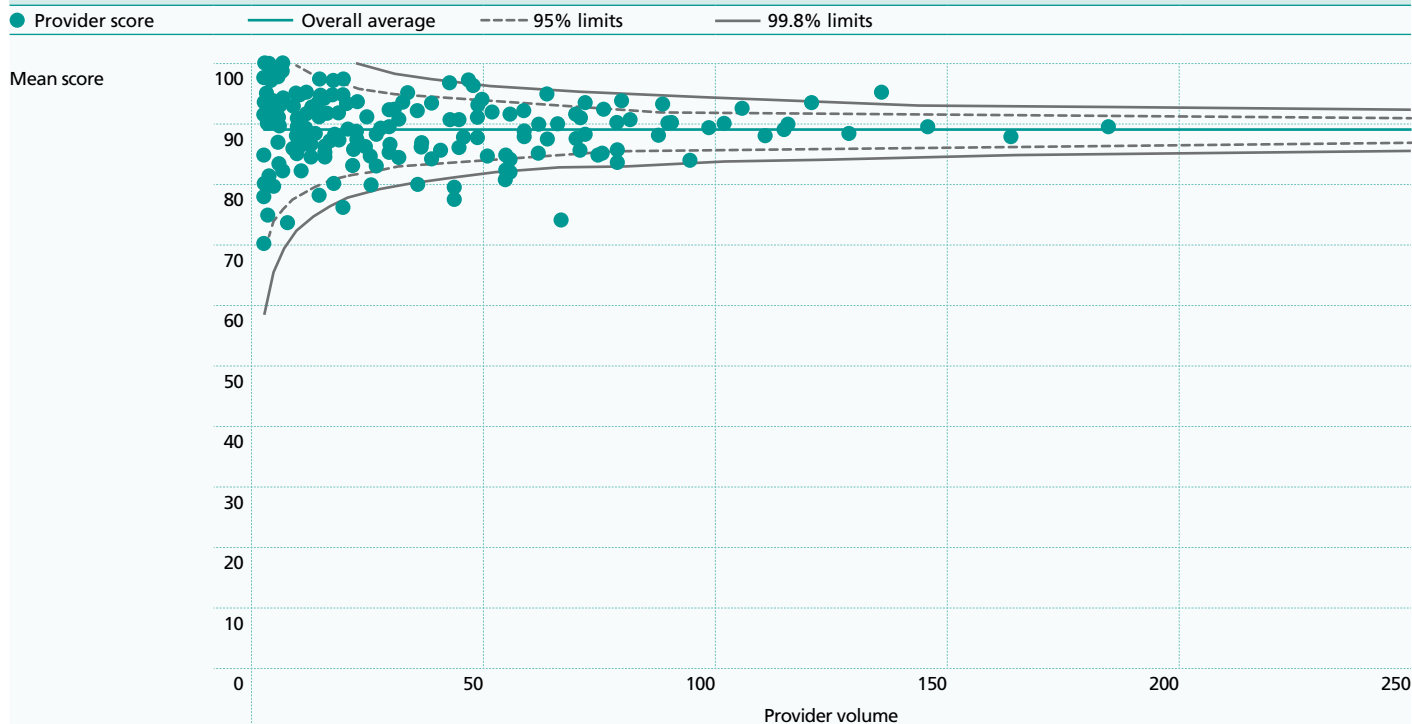
**Table 5.3**  
Levels of satisfaction with breast cancer clinical team (doctors and nurses) at 3 months after surgery

Information domain	Percentage of women who were very satisfied *		
	Mastectomy only (%)	Immediate Reconstruction (%)	Delayed Reconstruction (%)
Were professional?	86	84	86
Treated you with respect?	87	84	87
Were knowledgeable?	82	78	79
Were friendly and kind?	87	84	86
Made you feel comfortable?	86	82	84
Were thorough?	82	79	80
Made time for your concerns?	80	77	79

\* Response options were: very dissatisfied, dissatisfied, satisfied or very satisfied

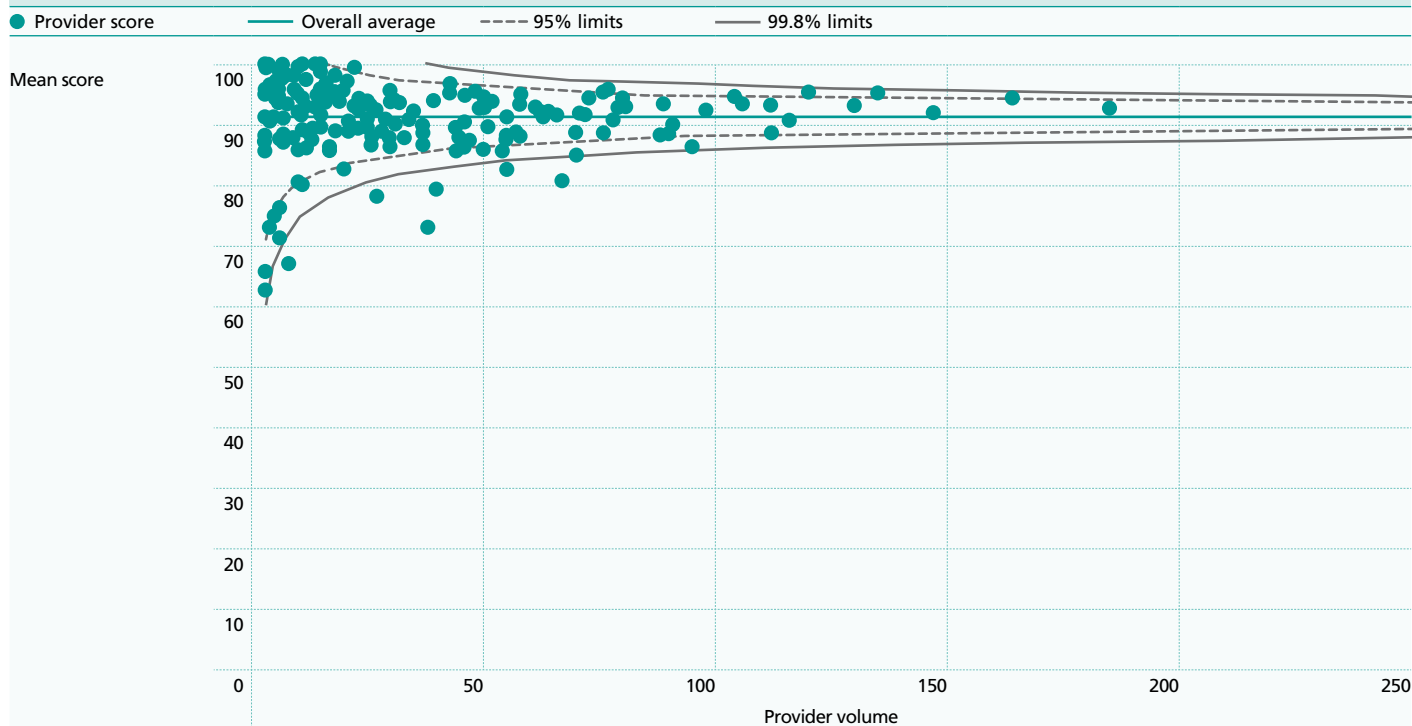


**Figure 5.1**  
Adjusted mean scores for “satisfaction with consultant surgeon” for hospital organisations, based on women’s responses on the 3 month post surgery questionnaire



\* Scores adjusted for age of the women at time of surgery

**Figure 5.2**  
Adjusted mean scores for “satisfaction with clinical team” for hospital organisations, based on women’s responses on the 3 month post surgery questionnaire



\* Scores adjusted for age of the women at time of surgery



## 6. Patient reported outcomes 18 months after surgery

In this chapter, we provide item-level summaries for the outcome measurement scales used in the 18 month patient questionnaires. Comparative analyses of the adjusted mean scores across hospital organisations are included in Chapter 7. These overall summaries are provided to assist clinicians in counselling their patients preoperatively about the anticipated results of their surgery. In addition to the outcome measurement scales, we also present figures for how women felt about the overall results of the procedure they underwent.

The figures are provided separately for women who had a mastectomy only, mastectomy with immediate breast reconstruction, or a delayed reconstruction. However, they should not be interpreted as giving information of the relative effectiveness of the various procedures. Each procedure is associated with distinct and different treatment pathways. In particular, there is a fundamental difference between immediate and delayed reconstruction in terms of a woman's reference point. Immediate reconstruction patients can only compare their reconstructed breast mound to their breast prior to mastectomy, while delayed reconstruction patients have the additional experience of having been without their breast following mastectomy.

In addition, patient-reported outcomes can be susceptible to a "response shift". This occurs if a subject's views, values or expectations change over the course of a study. The wait for delayed reconstruction after mastectomy could lead to a response shift among this group of patients compared to the group undergoing immediate reconstruction.

### 6.1 Overall experience

How women felt about the overall results of the procedure they underwent is summarised in [Table 6.1](#). Nationally, three-quarters of the mastectomy and delayed reconstruction patients and two-thirds of immediate reconstruction patients treated during the Audit period described the results of their surgery as excellent or very good. This is a real achievement by the breast cancer clinical community, and hospital organisations should try to ensure that they continue to attain these high ratings.

We also asked women about their satisfaction with the reconstructive options they were provided before and, in some cases, after their mastectomy surgery ([Table 6.2](#)). Just half of mastectomy-only patients were very satisfied with their options compared to two-thirds of immediate reconstruction and three-quarters of delayed reconstruction patients. These differences are likely to reflect the information and choices provided to women in the preoperative period and the time provided in which to consider these options. We asked about women's satisfaction with reconstructive information and choices in the 3 month patient questionnaires, and noted that mastectomy-only patients were much less satisfied than those who underwent reconstruction.<sup>18</sup> The figures in [Table 6.2](#) show that this dissatisfaction persists 18 months after surgery and is not simply a transient phenomenon.

**Table 6.1**  
Patients' rating of the results of their surgery at 18 months postoperatively

Overall, how would you describe the results of your operation?	Mastectomy only	Immediate reconstruction	Delayed reconstruction
Excellent	1,513 (36)	520 (34)	368 (47)
Very good	1,565 (37)	505 (33)	242 (31)
Good	786 (19)	288 (19)	101 (13)
Fair	304 (7)	145 (9)	43 (5)
Poor	74 (2)	74 (5)	28 (4)

**Table 6.2**  
Patients' rating of reconstructive information provision 18 months after their surgery

Overall, how satisfied are you with the options you have been given about breast reconstruction surgery since the time of your original diagnosis?	Mastectomy only	Immediate reconstruction	Delayed reconstruction
Very satisfied	1,842 (50)	993 (65)	572 (73)
Somewhat satisfied	1,142 (31)	418 (27)	162 (21)
Somewhat dissatisfied	454 (12)	80 (5)	30 (4)
Very dissatisfied	274 (7)	46 (3)	20 (3)

## 6.2 Outcomes of mastectomy surgery

The 18 month questionnaires asked women about their satisfaction with the postoperative appearance of the breast area, and their physical well-being, emotional well-being and sexual well-being. Responses to these questions were collected from both women who underwent mastectomy only or who had breast reconstruction surgery.

Table 6.3 summarises national data from the 18 month questionnaires for women who underwent mastectomy only. Except for physical well-being, Table 6.3 shows a trend down the items towards lower levels of satisfaction. This is to be expected and reflects the design of the scale in which the items measures aspects of satisfaction that are increasingly hard to achieve. The information is important to disseminate so that women have a realistic idea of what to expect from a mastectomy.

Eight out of ten women were, when clothed, satisfied with the postoperative appearance of the breast area following mastectomy. When unclothed, the proportion was much lower, with less than half being satisfied. The physical well-being of women was good in general; with typically less

than one in ten women reporting each particular physical symptom or impairment. Three-quarters of women felt confident in a social setting for most or all of the time, while around two-thirds reported feeling feminine in their clothes and self-confident. The proportion of women who felt attractive most or all of the time following mastectomy was 45 per cent. The proportion that gave positive responses to each of the sexual well-being questions was typically under 40 per cent.

The interpretation of the responses to the questions on sexual well-being requires care. Women could choose not to answer some or all of these questions, either by indicating that they did not wish to do so using a tick box provided for this purpose, or by selecting the “not applicable” response for particular options. Across the various age groups, the proportion of women who underwent mastectomy only who chose not to answer these questions was around a quarter for women under 40 years, around a third for women aged 40 to 49 years, around half for women aged 50 to 59 years, and around two-thirds for women aged 60 to 69 years. Over 85 per cent of women aged 70 years or over did not respond to these questions.

**Table 6.3**

**Responses of women who underwent mastectomy only to the items within the scales for satisfaction with breast area, physical well-being, emotional well-being and sexual well-being**

<b>Satisfaction with the postoperative appearance of the breast area</b>	<b>Women who were satisfied or very satisfied (%)</b>
How you look in the mirror <u>clothed</u> ?	83
How comfortably your bras fit?	73
Being able to wear clothing that is more fitted?	65
How you look in the mirror <u>unclothed</u> ?	42
<b>Physical well-being</b>	<b>Most or all of the time (%)</b>
How often have you experienced:	
Neck pain?	7
Upper back pain?	6
Shoulder pain?	10
Arm pain?	12
Rib pain?	6
Pain in the muscles of your chest?	7
Difficulty lifting or moving your arms?	9
Difficulty sleeping because of discomfort in your breast area?	7
Tightness in your breast area?	12
Pulling in your breast area?	9
A nagging feeling in your breast area?	7
Tenderness in your breast area?	10
Sharp pains in your breast area?	4
Shooting pains in your breast area?	3
An aching feeling in your breast area?	5
A throbbing feeling in your breast area?	2
** Swelling (lymphoedema) of the arm on the side that you had your mastectomy surgery? *	14
<b>Emotional well-being</b>	<b>Most or all of the time (%)</b>
How often have you felt:	
Confident in a social setting?	77
Emotionally able to do the things that you want to do?	73
Emotionally healthy?	71
Of equal worth to other women?	72
Self-confident?	68
Feminine in your clothes?	63
Accepting of your body?	62
Normal?	60
Like other women?	57
Attractive?	45
<b>Sexual well-being</b>	<b>Most or all of the time (%)</b>
How often have you felt:	
Sexually attractive in your clothes?	37
Comfortable/at ease during sexual activity?	39
Confident sexually?	34
Satisfied with your sex-life?	41
Confident sexually about how your breasts look when unclothed?	18
Sexually attractive when unclothed?	15

**\*\* This item was added to the RCS questionnaire used in the Audit and is not part of the standard Breast-Q scale**

### 6.3 Outcomes of immediate reconstruction

This section summarises the responses of women who underwent immediate reconstruction to the questions in the 18 month questionnaire. This information is important to disseminate so that women have a realistic idea of what to expect from an immediate reconstruction. The interpretation of these outcomes must consider the treatment pathways and position within these pathways of women undergoing immediate reconstruction. Women in the immediate reconstruction group had a relatively low tumour burden and were less likely to have had radical axillary surgery compared to women undergoing mastectomy only.<sup>5</sup>

Table 6.4 summarises the item responses about the appearance of the breast area following immediate reconstruction. The scale for women undergoing reconstruction contained 16 distinct items. The expected trend down the items towards lower levels of satisfaction again reflects the design of the scale in which the items measure aspects of appearance for which satisfaction is increasingly hard to achieve.

Nine out of ten women were, when clothed, satisfied with the postoperative appearance of the breast area, and three-quarters were satisfied with how comfortably their bras fitted. Two-thirds of women reported feeling satisfied that the reconstructed breast felt like a natural part of their body. When unclothed, six out of ten women were satisfied with how they looked in the mirror.

Around one-fifth of women were not satisfied with the size of their reconstructed breast in comparison to their unaffected breast, while one-third were dissatisfied with how closely their breasts matched each other when unclothed. To address these issues, clinicians may need to consider

alternative types of primary reconstruction or anticipate the need for additional surgery to the other breast to help achieve symmetry. The findings should also be highlighted when informing women before their surgery.

Table 6.5 describes women's responses to the items on physical well-being, emotional well-being and sexual well-being at 18 months after their mastectomy and immediate breast reconstruction. The proportion of women who reported continuing pain and discomfort following surgery was small, with 4 to 8 per cent of women experiencing particular problems. A slightly higher proportion of women reported tightness or pulling in the breast area.

Eight of ten women reported feeling confident in a social setting for most or all of the time, while around three-quarters reported feeling and feminine in their clothes and self-confident. After immediate reconstruction, the proportion of women who felt attractive most or all of the time was 60 per cent, and two-thirds reported feeling like other women most or all of the time. Just over half of the women reported feeling satisfied with their sex life, and sexually attractive in their clothes most or all of the time. One-third felt sexually attractive when unclothed most or all of the time.

As we noted earlier, women could choose not to answer some or all of the items on the sexual well-being scale. Across the various age groups, the proportion of women who underwent immediate reconstruction who chose not to answer these questions was around 20 per cent for women under 50 years, around a third for women aged 50 to 59 years, and around half for women aged 60 to 69 years. Few women over 70 years underwent an immediate breast reconstruction.

**Table 6.4**  
Satisfaction with the postoperative appearance of the breast area after immediate breast reconstruction

	Women who were satisfied or very satisfied (%)
How you look in the mirror <u>clothed</u> ?	90
The shape of your reconstructed breast when you are wearing a bra?	89
How normal you feel in your clothes?	91
The size of your reconstructed breast?	81
Being able to wear clothing that is more fitted?	82
How your breasts (unclothed) are lined up in relation to each other?	67
How comfortably your bras fit?	76
The softness of your reconstructed breast?	73
How equal in size your breasts are to each other (unclothed)?	64
How natural your reconstructed breast looks (unclothed)?	65
How naturally your reconstructed breast sits/hangs (unclothed)?	71
How your reconstructed breast feels to touch?	71
How much your reconstructed breast feels like a natural part of your body?	68
How closely matched your breasts are to each other (unclothed)?	61
How your reconstructed breast looks now compared to before you had any breast surgery?	61
How you look in the mirror <u>unclothed</u> ?	59

**Table 6.5**

**Responses of women who underwent immediate reconstruction to the items within the scales for physical well-being, emotional well-being and sexual well-being at 18 months**

<b>Physical well-being</b>	<b>Most or all of the time (%)</b>
How often have you experienced:	
Neck pain?	4
Upper back pain?	6
Shoulder pain?	8
Arm pain?	8
Rib pain?	4
Pain in the muscles of your chest?	4
Difficulty lifting or moving your arms?	6
Difficulty sleeping because of discomfort in your breast area?	8
Tightness in your breast area?	14
Pulling in your breast area?	12
A nagging feeling in your breast area?	8
Tenderness in your breast area?	7
Sharp pains in your breast area?	3
Shooting pains in your breast area?	3
An aching feeling in your breast area?	4
A throbbing feeling in your breast area?	2
** Swelling (lymphoedema) of the arm on the side that you had your mastectomy surgery?*	6
<b>Emotional well-being</b>	<b>Most or all of the time (%)</b>
How often have you felt:	
Confident in a social setting?	85
Emotionally able to do the things that you want to do?	80
Emotionally healthy?	78
Of equal worth to other women?	78
Self-confident?	75
Feminine in your clothes?	78
Accepting of your body?	70
Normal?	68
Like other women?	67
Attractive?	61
<b>Sexual well-being</b>	<b>Most or all of the time (%)</b>
How often have you felt:	
Sexually attractive in your clothes?	57
Comfortable/at ease during sexual activity?	48
Confident sexually?	47
Satisfied with your sex-life?	52
Confident sexually about how your breasts look when unclothed?	35
Sexually attractive when unclothed?	32

**\*\* This item was added to the RCS questionnaire used in the Audit and is not part of the standard Breast-Q scale**

## Satisfaction with implants

The majority of immediate reconstructive procedures undertaken in England involve a tissue expander or fixed volume implant with or without flap coverage. For this reason, we ensured that the 18 month patient questionnaire included a specific scale for this type of surgery. Throughout this section the term “implant” will be used to refer to both expanders and implants. In this section, we provide an item-level breakdown of the implant scale.

Table 6.6 gives the item-level satisfaction scores for the implant scale for women whose immediate reconstruction involved an implant, with or without a flap. The combined scores for women being either satisfied or very satisfied are slightly higher for implants with flap coverage. The difference increases when looking at just the very satisfied response: 38 per cent of women who underwent immediate implant-only reconstruction were very satisfied with the extent to which the implant could not be seen or felt, whereas around 52 per cent of women with concurrent pedicle flap coverage were very satisfied.

## Satisfaction with flap donor site: reconstruction using tissue from the back

Most flap-based breast reconstruction involves tissue being taken from the back or the abdomen. In the 18 month questionnaires, women were asked about the appearance and disability associated with these donor sites following surgery. Only those women who had undergone flap reconstruction using tissue from the relevant area completed the scales.

Tables 6.7 and 6.8 give the results of the back and shoulder-specific scales completed by women who underwent latissimus dorsi (back muscle) pedicle flap immediate reconstruction, with or without an implant. We provided this data categorised by implant use because, in some women, the latissimus dorsi muscle is used simply to cover an implant, while in others it is moved along with additional tissue and used to reconstruct the breast on its own. Around 1 in 10 women were bothered most or all of the time with particular aspects of the appearance of their back (Table 6.7) but greater proportions reported problems with activities involving back and shoulder muscles (Table 6.8).

**Table 6.6**  
Satisfaction with implants at 18 months postoperatively among women having immediate breast reconstruction

	Women who were satisfied or very satisfied (%)	
	Implant-only	Implant with flap coverage
The amount of rippling (wrinkling or creasing) of your implant that you can <u>see</u> ?	72	84
The amount of rippling (wrinkling or creasing) of your implant that you can <u>feel</u> ?	71	82

**Table 6.7**  
Satisfaction with back donor site appearance (latissimus dorsi flap patients) among women who had an immediate reconstruction

How often have you been bothered by:	Women bothered by these issues most or all of the time (%)	
	LD with implant	Autologous LD
How your back looks?	10	13
The shape (contour) of your back?	11	13
The sides of your back not matching?	10	12
How your back <u>scar</u> looks?	10	14
The <u>location</u> of your back scar?	6	8
The <u>length</u> of your back scar?	7	10
How noticeable your back scar is to others?	8	9
Having to wear certain clothes in order to <u>hide</u> your back scar?	13	13
<u>Not</u> being able to wear certain clothes because of your back scar (eg backless dress, bathing suit)?	14	15

Tables 6.9 and 6.10 give the results of the abdomen-specific scales completed by women who underwent TRAM (pedicled or free), DIEP or SIEA flap reconstruction at the time of their mastectomy. Almost none of these women had reconstruction that also involved an implant.

Only a small minority of women reported functional problems related to their abdominal donor site (Table 6.9). Nearly three-quarters of women were satisfied with the

appearance of their abdomen and how it looked and felt 18 months after their reconstruction (Table 6.10). Around one-third of women were very satisfied with how their abdomen looked and felt 18 months after surgery compared to before their surgery.

**Table 6.8**  
Experience of back and shoulder functional impairment (latissimus dorsi flap patients) among women who had an immediate reconstruction

How often have you experienced:	Women who have experienced these issues most or all of the time (%)	
	LD with implant	Autologous LD
Back pain?	11	13
Shoulder pain?	8	8
An aching feeling in your <u>back</u> area?	10	15
An aching feeling in your <u>shoulder</u> area?	7	10
Shoulder stiffness?	7	9
Tightness when you stretch your arm?	19	20
A pulling feeling in your back?	19	24
Weakness in your arm?	17	14
Difficulty <u>lifting</u> heavy objects (eg large bag of groceries)?	20	24
Difficulty <u>carrying</u> heavy objects (eg large bag of groceries)?	20	25
Difficulty <u>reaching</u> for objects (eg taking something down from a high shelf)?	21	22
Difficulty doing activities with your arms <u>outstretched</u> (eg vacuuming, shovelling)?	14	15
Difficulty doing activities with your arms <u>above your head</u> (eg doing up dress zipper, styling your hair)?	12	14
Difficulty doing activities that <u>repeatedly</u> use shoulder & back muscles (eg throwing a ball, playing tennis, swimming)?	17	20

**Table 6.9**  
Patient experience of abdominal functional impairment (TRAM/DIEP flap patients)

How often have you experienced:	Women who experienced these issues most or all of the time (%)
Difficulty sitting up because of abdominal muscle weakness (eg getting out of bed)?	6
Difficulty doing everyday activities because of abdominal muscle weakness (eg making your bed)?	3
Abdominal discomfort?	10
Abdominal bloating?	8
Abdominal bulging?	12
Tightness in your abdomen?	13
Pulling in your abdomen?	10
Lower back pain?	12

**Table 6.10**  
Patient satisfaction with abdominal appearance (TRAM/DIEP flap patients)

Abdominal appearance	Women who were satisfied or very satisfied (%)
How your abdomen looks?	73
The position of your navel (belly button)?	84
How your abdominal scars look?	71
	Women who were satisfied or very satisfied (%)
How your abdomen feels now compared to before your surgery?	72
How your abdomen looks now compared to before your surgery?	73

At many hospital organisations, women are shown photos of previous postoperative results and meet women who have been through the particular type of surgery they are considering. This summary of the experiences of women undergoing immediate breast reconstruction collected during the Audit can be used to augment the information about outcomes obtained from one or more local volunteers whose background, cancer treatments and age may differ significantly from the woman making reconstructive decisions.

#### 6.4 Outcomes of delayed breast reconstruction

This section summarises the responses of women who underwent delayed reconstruction to the questions in the 18 month questionnaire. This information is important to disseminate so that women have a realistic idea of what to expect from this procedure. The interpretation of these outcomes must consider the treatment pathway involved. Although all women in the Audit responded to these questions 18 months after their primary cancer treatment, the elapsed time since their original breast cancer diagnosis was substantially longer (and more variable) for women who had a delayed reconstruction. Delayed reconstruction patients had also experienced a period of living without a breast following mastectomy, which is likely to have influenced their ratings of quality of life post-reconstruction.

Table 6.11 summarises the item responses about the appearance of the breast area following delayed reconstruction. The scale for women undergoing reconstruction contained 16 distinct items. There is a small trend down the items towards lower levels of satisfaction, which reflects the design of the scale in which the items measures aspects of satisfaction that are increasingly hard to achieve.

Over 90 per cent of women were, when clothed, satisfied with the postoperative appearance of the breast area, while 86 per cent were satisfied with how comfortably their bras fitted. Eight out of ten women reported feeling satisfied that the reconstructed breast felt like a natural part of their body. When unclothed, three-quarters of women were satisfied with how they looked in the mirror.

Around one-fifth of women were not satisfied with the size of their reconstructed breast in comparison to their unaffected breast, while three in ten were not satisfied with how closely their breasts matched each other when unclothed. As with immediate reconstruction procedures, these figures raise the issues of whether alternative primary reconstructive options may need to be considered and, if surgery to the other breast to improve symmetry needs to be undertaken, this should be discussed when informing women of what is involved.

**Table 6.11**  
**Satisfaction with the postoperative appearance of the breast area after delayed breast reconstruction**

	Women who were satisfied or very satisfied (%)
How you look in the mirror <u>clothed</u> ?	93
The shape of your reconstructed breast when you are wearing a bra?	92
How normal you feel in your clothes?	95
The size of your reconstructed breast?	86
Being able to wear clothing that is more fitted?	88
How your breasts (unclothed) are lined up in relation to each other?	77
How comfortably your bras fit?	86
The softness of your reconstructed breast?	86
How equal in size your breasts are to each other (unclothed)?	73
How natural your reconstructed breast looks (unclothed)?	79
How naturally your reconstructed breast sits/hangs (unclothed)?	83
How your reconstructed breast feels to touch?	84
How much your reconstructed breast feels like a natural part of your body?	83
How closely matched your breasts are to each other (unclothed)?	72
How your reconstructed breast looks now compared to before you had any breast surgery?	85
How you look in the mirror <u>unclothed</u> ?	76



Table 6.12 describes women's responses to the items on physical well-being, emotional well-being and sexual well-being at 18 months after their delayed reconstruction. Women reported good levels of physical well-being, with between 1 and 9 per cent of women reporting continuing pain and discomfort related to particular problems. Emotional well-being was also rated very positively. Nine out of ten women reported feeling confident in a social setting for most or all of the time, while over 80 per cent reported feeling feminine in their clothes and self-confident.

The proportion that felt attractive most or all of the time after delayed reconstruction was 70 per cent, while 80 per cent of women reported feeling like other women most or all of the time. Six out of ten women reported feeling satisfied with their sex-life, while slightly more felt sexually attractive in their clothes most or all of the time. Just under half of the women reported feeling sexually attractive when unclothed most or all of the time at 18 months after their delayed reconstruction.

**Table 6.12**

**Responses of women who underwent delayed reconstruction to the items within the scales for physical well-being, emotional well-being and sexual well-being at 18 months**

Physical well-being	Most or all of the time (%)
How often have you experienced:	
Neck pain?	5
Upper back pain?	6
Shoulder pain?	7
Arm pain?	9
Rib pain?	4
Pain in the muscles of your chest?	4
Difficulty lifting or moving your arms?	6
Difficulty sleeping because of discomfort in your breast area?	5
Tightness in your breast area?	9
Pulling in your breast area?	8
A nagging feeling in your breast area?	5
Tenderness in your breast area?	4
Sharp pains in your breast area?	2
Shooting pains in your breast area?	2
An aching feeling in your breast area?	2
A throbbing feeling in your breast area?	1
** Swelling (lymphoedema) of the arm on the side that you had your mastectomy surgery?*	13
<b>Emotional well-being</b>	<b>Most or all of the time (%)</b>
How often have you felt:	
Confident in a social setting?	92
Emotionally able to do the things that you want to do?	88
Emotionally healthy?	88
Of equal worth to other women?	83
Self-confident?	82
Feminine in your clothes?	85
Accepting of your body?	80
Normal?	79
Like other women?	76
Attractive?	69
<b>Sexual well-being</b>	<b>Most or all of the time (%)</b>
How often have you felt:	
Sexually attractive in your clothes?	68
Comfortable/at ease during sexual activity?	62
Confident sexually?	60
Satisfied with your sex-life?	60
Confident sexually about how your breasts look when unclothed?	50
Sexually attractive when unclothed?	47

\*\* This item was added to the RCS questionnaire used in the Audit and is not part of the standard Breast-Q scale

As we noted earlier, women could choose not to answer some or all of the items on the sexual well-being scale. Across the various age groups, the proportion of delayed reconstruction patients who chose not to answer these questions increased roughly by 10 per cent for every 10 year increase in age, going from 20 per cent for women under 40 years to nearly 60 per cent for women aged 60 to 69 years. Few women over 70 years underwent a delayed breast reconstruction.

## Satisfaction with implants

Around 40 per cent of delayed reconstructive procedures undertaken in England involve a tissue expander or fixed volume implant with or without flap coverage. The 18 month patient questionnaire included a specific scale to capture outcomes for this type of surgery. In this section, we provide an item-level breakdown of the implant scale. The term “implant” will be used to refer to both expanders and implants.

The item-level satisfaction scores for the implant scale are given in Table 6.13. The results are provided for all women whose reconstruction involved an implant, with or without a flap. As coverage of an implant with a flap of the patient's own tissue reduces its visibility and prominence to touch, we have provided data separately for women whose reconstruction also involved a flap.

The combined scores show that over 85 per cent of women were either satisfied or very satisfied. Half of those women who underwent delayed implant-only reconstruction were very satisfied with the extent to which the implant could not be seen. The proportion was slightly higher among women with concurrent pedicle flap coverage with 64 per cent being very satisfied.

These figures are not directly comparable to those reported for immediate breast reconstruction. These women had previously lived without a breast mound for a period, and this experience is likely to have greatly influenced their perceptions and point of comparison. Furthermore, a relatively small and select group of mastectomy patients go on to undergo delayed reconstruction and those in this group may have specific aesthetic concerns. Finally, as these women were not under any time pressure while making reconstructive decisions, those who chose to undergo implant-based reconstruction are likely to have made their decision with better and more complete information about the various options available and what to expect.

## Satisfaction with flap donor site: reconstruction using tissue from the back

Most flap-based breast reconstruction involves tissue being taken from the back or the abdomen. In the 18 month questionnaires, women were asked about the appearance and disability associated with these donor sites following surgery. Only those women who had undergone flap reconstruction using tissue from the relevant area completed the scales.

Tables 6.14 and 6.15 give the results of the back and shoulder-specific scales completed by women who underwent delayed latissimus dorsi (back muscle) pedicle flap reconstruction, with or without an implant. A small minority of women were bothered most or all of the time with the appearance of their back but greater proportions reported problems with activities involving back and shoulder muscles.

**Table 6.13**  
Satisfaction with implants at 18 months postoperatively among women having delayed breast reconstruction

	Women who were satisfied or very satisfied (%)	
	Implant-only	Implant with flap coverage
The amount of rippling (wrinkling or creasing) of your implant that you can <u>see</u> ?	87	90
The amount of rippling (wrinkling or creasing) of your implant that you can <u>feel</u> ?	85	86

**Table 6.14**  
Satisfaction with back donor site appearance (latissimus dorsi flap patients) among women who had a delayed reconstruction

How often have you been bothered by:	Women bothered by these issues most or all of the time (%)	
	LD with implant	Autologous LD
How your back looks?	6	10
The shape (contour) of your back?	5	9
The sides of your back not matching?	4	11
How your back <u>scar</u> looks?	8	11
The <u>location</u> of your back scar?	6	7
The <u>length</u> of your back scar?	9	7
How noticeable your back scar is to others?	7	10
Having to wear certain clothes in order to <u>hide</u> your back scar?	11	13
<u>Not</u> being able to wear certain clothes because of your back scar (eg backless dress, bathing suit)?	12	16

Women undergoing autologous delayed reconstruction were much more likely to be bothered by the appearance of their back than those undergoing implant-assisted delayed reconstruction. In both cases, the skin requirements to reconstruct the breast mound were similar. However, those in whom an implant was not used would probably have needed more tissue to be taken from the back, and this appears to reduce their satisfaction with the postoperative appearance of the donor site.

### Satisfaction with flap donor site: reconstruction using tissue from the abdomen

Tables 6.16 and 6.17 give the results of the abdomen-specific scales completed by women who underwent delayed TRAM (pedicled or free), DIEP or SIEA flap reconstruction. Almost none of these women had reconstruction that also involved an implant.

Only a small minority of women reported functional problems related to their abdominal donor site (Table 6.16). Over 80 per cent of women were satisfied with the appearance of their abdomen and how it looked and felt 18 months after their reconstruction (Table 6.17). Around 45 per cent of women were very satisfied with how their abdomen looked and felt at 18 months after surgery compared to before their surgery.

**Table 6.15**  
Experience of back and shoulder functional impairment (latissimus dorsi flap patients) among women who had a delayed reconstruction

How often have you experienced:	Women who have experienced these issues most or all of the time (%)	
	LD with implant	Autologous LD
Back pain?	6	10
Shoulder pain?	6	7
An aching feeling in your <u>back</u> area?	8	14
An aching feeling in your <u>shoulder</u> area?	5	9
Shoulder stiffness?	6	5
Tightness when you stretch your arm?	13	18
A pulling feeling in your back?	11	17
Weakness in your arm?	16	16
Difficulty <u>lifting</u> heavy objects (eg large bag of groceries)?	20	21
Difficulty <u>carrying</u> heavy objects (eg large bag of groceries)?	23	22
Difficulty <u>reaching</u> for objects (eg taking something down from a high shelf)?	18	20
Difficulty doing activities with your arms <u>outstretched</u> (eg vacuuming, shovelling)?	12	15
Difficulty doing activities with your arms <u>above your head</u> (eg doing up dress zipper, styling your hair)?	14	15
Difficulty doing activities that <u>repeatedly</u> use shoulder & back muscles (eg throwing a ball, playing tennis, swimming)?	14	19

**Table 6.16**  
Patient experience of abdominal functional impairment (TRAM/DIEP flap patients) among women who underwent delayed reconstruction

How often have you experienced:	Women who experienced these issues most or all of the time (%)
Difficulty sitting up because of abdominal muscle weakness (eg getting out of bed)?	3
Difficulty doing everyday activities because of abdominal muscle weakness (eg making your bed)?	2
Abdominal discomfort?	5
Abdominal bloating?	6
Abdominal bulging?	10
Tightness in your abdomen?	11
Pulling in your abdomen?	8
Lower back pain?	12

**Table 6.17**  
Patient satisfaction with abdominal appearance (TRAM/DIEP flap patients) among women who underwent delayed reconstruction

Abdominal appearance	Women who were satisfied or very satisfied (%)
How your abdomen looks?	82
The position of your navel (belly button)?	88
How your abdominal scars look?	76
	Women who were satisfied or very satisfied (%)
How your abdomen <u>feels</u> now compared to before your surgery?	83
How your abdomen <u>looks</u> now compared to before your surgery?	81

## 6.5 Outcomes for different mastectomy and reconstruction procedures

Table 6.18 describes the mean outcome scores, unadjusted and adjusted, for the main scales used in the 18 month questionnaires, broken down by type of reconstructive procedure. Scores were adjusted for women's age, deprivation index, performance status, smoking status, and whether they had undergone radiotherapy and/or chemotherapy postoperatively.

The aesthetic outcome assessment scale for the breast area used for mastectomy patients differs from that used following reconstruction. For that reason, the cosmetic scores for the patient groups are not directly comparable. However, women who underwent breast reconstruction (in particular, a pedicle or free flap reconstruction) reported higher levels of emotional and sexual well being than those who underwent mastectomy. Physical well being did not vary greatly across the various patient groups.

Satisfaction with breast area appearance varied most across the types of reconstruction following delayed reconstruction. This pattern was also evident for the scales on emotional and sexual well being. For satisfaction with breast area appearance and sexual wellbeing, the case-mix adjusted outcomes reported by women following delayed free flap reconstruction were better than those reported following delayed pedicle flap reconstruction with or without an implant. Both groups of women had higher scores than

that of the group who underwent delayed implant-only reconstruction. In contrast, the differences between the outcomes of women who underwent an immediate pedicle flap reconstruction and those who underwent immediate free flap reconstruction were minimal. However, women gave lower scores for aesthetic outcome and their emotional and sexual well following immediate implant-only reconstruction, the scores being similar to those of women who underwent mastectomy only.

In view of these findings, we would recommend that hospital organisations act to ensure that women in both the immediate and delayed reconstruction settings are provided with sufficient information and choices about the full range of reconstructive options. In particular, the results emphasise the importance of having access to complex reconstruction procedures at the time of mastectomy. The findings of the Audit should be used to augment the information provided to women about what they can expect after different types of surgery.

We again note that the differences between the different groups of women should be interpreted with caution. Women who had a delayed breast reconstruction have lived without a breast/breast mound for a period of time, and consequently, this could introduce a response shift. As a self-selecting group of mastectomy patients, they are also likely to be highly motivated and to be particularly concerned with the aesthetic results of their surgery.

**Table 6.18**  
Mean outcome scores categorised by type of surgery, unadjusted and adjusted for patient-case-mix

		Breast area appearance*		Emotional well being		Physical well being		Sexual well being	
		Unadj. Score	Adj. score	Unadj. Score	Adj. score	Unadj. Score	Adj. score	Unadj. score	Adj. score
<b>Mastectomy only</b>		56	56	63	63	73	73	38	39
IR	Implant-only	55	54	65	65	75	74	46	44
	Pedicle with implant	64	63	73	72	75	75	52	50
	Autologous pedicle flap	65	64	71	70	74	73	51	49
	Free flap	64	63	71	70	76	75	52	49
DR	Implant-only	57	56	66	66	76	76	51	49
	Pedicle flap with implant	68	68	75	76	75	76	58	58
	Autologous pedicle flap	69	69	74	74	76	77	56	56
	Free flap	73	73	78	78	79	80	64	63

\* the scale used to assess satisfaction with the breast area in mastectomy only patients contained a smaller number of items

# 7. NHS trust and hospital-level patient reported outcomes 18 months after surgery

## 7.1 Satisfaction with breast area

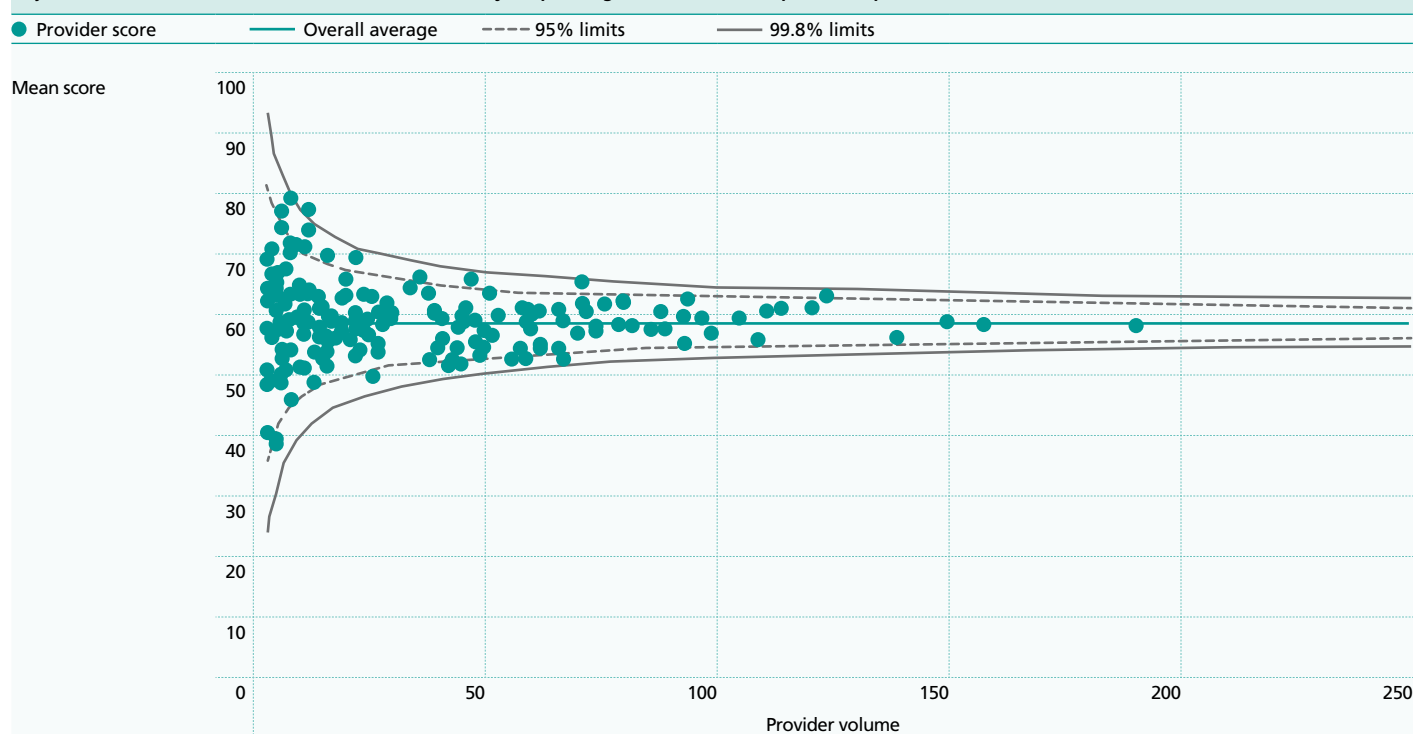
At 18 months after their mastectomy or reconstruction operation, women were asked about the aesthetic outcomes of their surgery. In this chapter, we provide the mean adjusted scores of the scale for satisfaction with the breast area at each participating NHS trust and independent hospital (Figure 7.1). One hospital organisation had an adjusted mean score that was above the upper 99.8 per cent control limit. No organisations had adjusted mean scores that were below the lower control limit.

In addition to the one hospital organisation that achieved a significantly higher mean score than the overall mean, there were several others close to the upper 99.8 per cent control limit. We suggest that their local practices are examined in more depth to see whether there are lessons that could be disseminated more widely.

## 7.2 Emotional well being

The next important domain covered in the 18 month questionnaires was psychosocial and emotional well being. The mean adjusted scores of NHS trusts and independent hospitals are displayed in Figure 7.2. This shows that one organisation had an adjusted mean score that was above the upper 99.8 per cent control limit. No organisation had adjusted mean scores that were below the lower control limit. This suggests a consistent level of care and surgical outcomes in terms of satisfaction with emotional well-being across all participating hospital organisations. Again, we would suggest that the local practices at the highly performing organisations are examined to see if any are transferable to other organisations.

**Figure 7.1**  
Adjusted mean scores for satisfaction with breast area by hospital organisation based on patient responses at 18 months



\* Scores adjusted for age, deprivation, functional status, current/non-smoker, procedure type and the use of postoperative radiotherapy and/or postoperative chemotherapy.

7.3 Physical well being

Figure 7.3 gives the mean adjusted scores for physical well being at participating organisations in the Audit. All but one participating hospital organisation had adjusted mean scores that were within the range that would be expected due to random fluctuations alone; the one exception had an adjusted mean score that was below the lower 99.8 per cent control limit. As we have previously mentioned, the Audit only included the subset of hospital organisations that chose to participate in the patients reported outcomes study. This makes it difficult to make conclusions about those whose adjusted mean scores are lower than the overall average. However, we would recommend that all organisations review their practice to identify areas in which support and care may be improved to benefit the women they treat.

7.4 Sexual well being

Figure 7.4 gives the mean adjusted scores for sexual well being at participating organisations in the Audit. All organisations had adjusted mean scores that were within the range that would be expected due to random fluctuations alone. The number of respondents was lower for this scale, and the proportion with incomplete data varied across hospital organisations. As we expected some women to feel that these issues were not relevant to them or too personal to complete, we included a skip option for the scale and 'not applicable' options for each of the items. These results are also likely to reflect many issues that cannot be dealt with by the surgical team.

For these reasons, we do not currently wish to make any specific recommendations in this area, but we note that the mean overall score is considerably lower than on the other scales. This suggests that it is worth continuing to look at this important component of quality of life.

7.5 High performing organisations

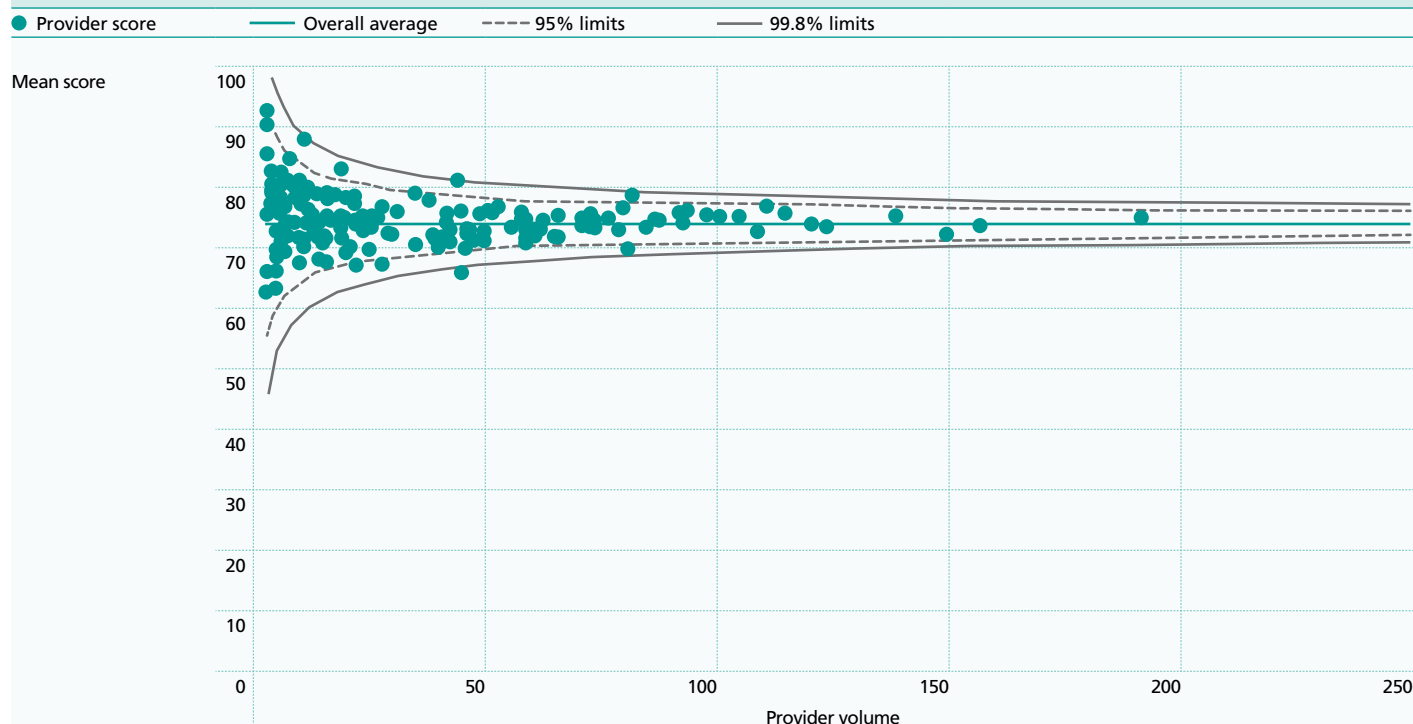
For each scale, we identified a range of mean outcome scores at participating hospital organisations. Most of this variation was within the range expected due to random fluctuations given the number of responses from women treated at that organisation (sample size). It appears that levels of performance across English hospital organisations are broadly similar. This is a very reassuring finding when one considers that women report high levels of satisfaction overall (see Chapter 6). We would recommend that the findings in this chapter are used to define a benchmark against which future outcomes may be compared.

A few hospital organisations were identified where patient-reported outcomes at 18 months were significantly better than those obtained nationally. We would like to commend these organisations for their work during the Audit period. Their results demonstrate what is achievable, and should be referred to by others to help identify specific areas of quality that could be extended more generally.



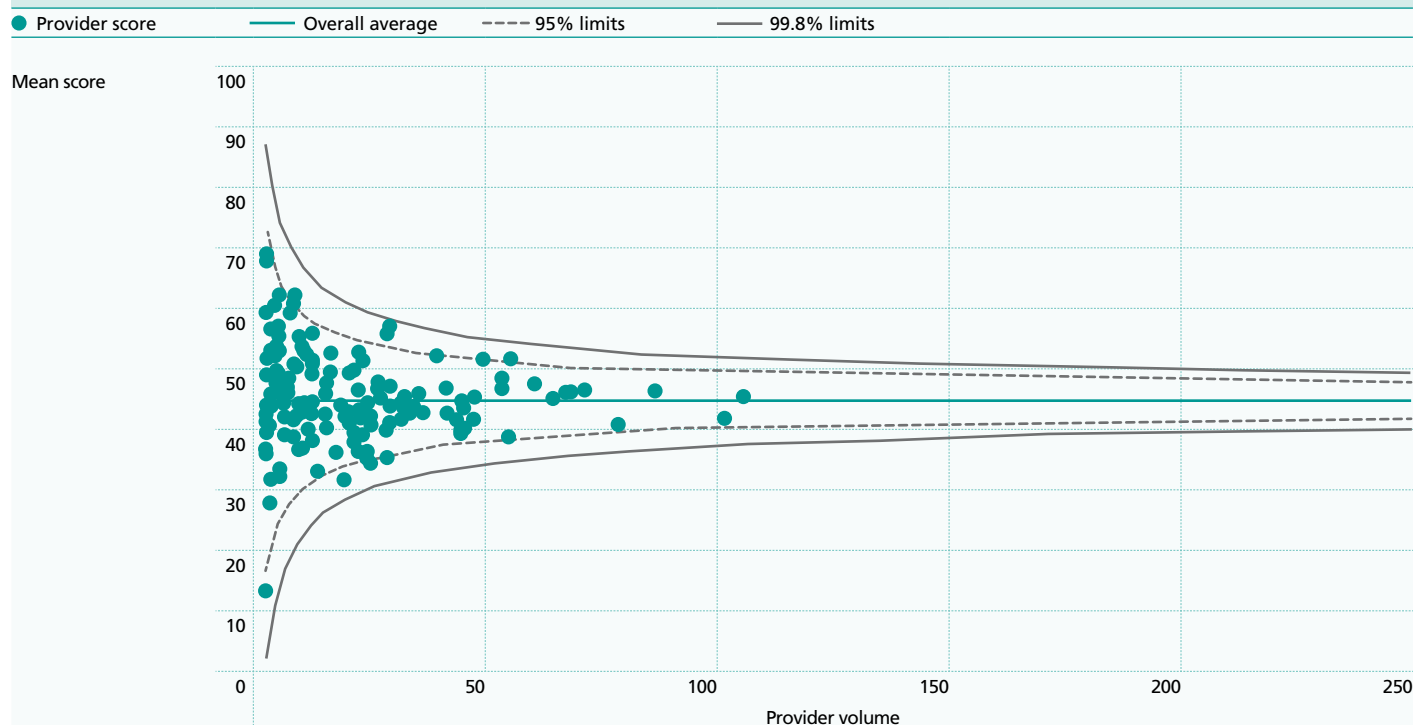
\* Scores adjusted for age, deprivation, functional status, current/non-smoker, procedure type and the use of postoperative radiotherapy and/or postoperative chemotherapy.

**Figure 7.3**  
Adjusted mean scores for satisfaction with physical well being by hospital organisation based on patient responses at 18 months



\* Scores adjusted for age, deprivation, functional status, current/non-smoker, procedure type and the use of postoperative radiotherapy.

**Figure 7.4**  
Adjusted mean scores for satisfaction with sexual well being by hospital organisation based on patient responses at 18 months





## 8. Conclusion

### 8.1 Implications for clinical practice

The Audit is the first national study of mastectomy and breast reconstruction surgery to be conducted worldwide. Our findings are that overall clinicians are providing high quality care to women with breast cancer undergoing mastectomy in England. In particular, the majority of women were very satisfied with the care they received, and the outcomes they attained following mastectomy and reconstruction surgery.

This is the first time that national data has demonstrated the effectiveness of breast reconstruction in improving quality of life following mastectomy. A benefit of this national perspective is that it produced information which is relevant to the whole population of women undergoing mastectomy. Women diagnosed with breast cancer should be informed of these findings, and clinicians should ensure that they are supported in making an informed decision about whether or not to have breast reconstruction surgery.

The data collected should also be used to inform women undergoing mastectomy of the likely outcomes of the different types of reconstruction, and what to expect when undergoing these procedures. This should augment the information already provided by local breast care teams, and help women to make informed decisions about reconstruction.

Finally, clinicians should address the specific issues raised by improving the training and knowledge base of general and plastic surgery trainees and nursing staff. They should also act to ensure that women undergoing mastectomy are able to meet their consultants when required to discuss both difficult decisions about the risks and benefits of complex procedures, and long term issues that may arise as a result of their breast cancer surgery and ancillary treatments.

We have only been able to report these findings due to the tremendous participation across NHS and independent hospital organisations, the support of the professional bodies and patient groups involved in breast cancer care, and of course the funding provided by the Healthcare Quality Improvement Partnership.

Participating organisations, and their multidisciplinary and management teams, need to review the key findings, identify areas in which local improvements are required, and act appropriately to inform women and improve the results of their surgery. These responses are the most important component of the Audit, and will help to ensure the provision of safe, effective and high quality care for women who are diagnosed with breast cancer.

### 8.2 Recommendations

#### Informing and counselling women

1. NHS trusts and independent hospitals should act to maintain the current high levels of satisfaction with both consultant surgeons and breast cancer teams.
2. NHS trusts and independent hospitals should ensure that women are able to be involved in decision making to the degree that they wish, and that staff are available to address the concerns of women undergoing cancer treatments and complex reconstructive procedures.
3. Clinicians should use the summary of the experiences of women undergoing breast reconstruction collected during the Audit to augment information about outcomes obtained from volunteers whose background, cancer treatments and age may differ significantly from the woman making reconstructive decisions.
4. Clinicians should inform women undergoing mastectomy that those who underwent breast reconstruction reported higher levels of emotional and sexual well being than those who underwent mastectomy alone.
5. NHS trusts and independent hospitals should act to ensure that women in both the immediate and delayed reconstruction settings are provided with sufficient information and choices about the full range of reconstructive options.

#### Continuing to achieve high quality outcomes

6. NHS trusts and independent hospitals should ensure that they continue to attain the excellent results of mastectomy and breast reconstruction surgery reported by patients.
7. The Audit findings represent the first national data of their type, and should be used by NHS trusts and hospital organisations to define a performance benchmark against which their future outcomes may be compared.
8. Those involved in the development of future guidelines on mastectomy and breast reconstruction should refer to the results of high achieving organisations when setting benchmarks for future audit.



# Appendix 1: Summary of the First, Second and Third Annual Reports

The First Annual Report, published in March 2008, described initial results of the Audit's evaluation of surgical services for women with breast cancer in England and Wales. Three separate but related studies were undertaken, all of which assessed different aspects of the provision of mastectomy and reconstruction surgery:

- a qualitative study of interviews with 30 stakeholders to highlight the characteristics of high quality surgical care for women with breast cancer
- an organisational survey of NHS acute trusts and independent hospitals to investigate service provision and reconstructive access
- an analysis of routine hospital data to describe trends in the number and type of breast cancer operations performed in the English NHS between 1997 and 2006.

The combined results of these studies suggested that breast cancer surgery services in England and Wales provided a high standard of care in difficult circumstances. Service providers were responding well to the rising incidence of breast cancer but concerns remained with certain aspects of the service (see Box, page 40). The most important issue identified was the unequal utilisation of immediate breast reconstruction across English regions.

The Second Annual Report focused on the use of reconstructive surgery for women with breast cancer and short-term surgical outcomes. The results were based on prospectively collected data and describe adult women who underwent mastectomy or reconstructive breast surgery between 1 January 2008 and 31 March 2009. The Audit received data from all 150 English NHS trusts and 106 independent hospitals. Six non-English NHS trusts also chose to participate. In total, clinical information was supplied on 17,059 women, of whom 85 per cent had invasive carcinoma. The remainder were being treated for ductal carcinoma in situ (DCIS).

The Second Annual Report highlighted that, over the past few years, the proportion of women having immediate reconstruction increased from approximately 11 per cent (between 1 April 2005 and 31 March 2006) to 21 per cent (between 1 January 2008 to 31 March 2009). Nonetheless, there was significant variation across English Cancer Networks in both the rates of reconstruction and the proportion of women offered it. This variation was not explained by the characteristics of the women undergoing mastectomy. The variation seen in the proportion of women who accepted an offer of immediate reconstruction may reflect the timing of the offer, the way in which it was communicated, and whether accepting the offer involved a delay in primary cancer treatment.

In addition, the higher use of implant (or tissue expander) only reconstructions in the immediate setting suggested that a proportion of women are not able to access all appropriate reconstructive options. This raised questions about how easily patients may be referred from breast to plastic surgery units, especially if the latter are not available locally.

The Third Annual Report focused on the process of surgical care and short-term outcomes and combined data from two sources: details of the women's condition, their treatment and outcomes while admitted to hospital; and information on post-discharge complications, experience of care and satisfaction with treatment options reported by women three months after their surgery.

Engagement with the patient-reported outcomes component of the Audit was variable among participating NHS trusts and independent hospitals, but response rates were excellent. Of 8,159 consented women sent a questionnaire three months after their surgery, 6,882 (84.3 per cent) responded.

Around 10 per cent of women undergoing mastectomy had a local complication. The proportion of mastectomy only and immediate reconstruction patients to experience a complication ranged from 15 per cent to 18 per cent for different procedures. Pedicle flap reconstructions involved an increased risk of flap donor site haematoma and seroma, while free-flap reconstructions involved an increased risk of re-examination in theatre.

Funnel plots of the case-mix and procedure adjusted rates for return to theatre, mastectomy-site complications and distant/systemic complications showed that trust and hospital-level rates did not differ significantly from the national rate. However, 50 organisations were excluded from this comparative analysis due to low case-ascertainment or incomplete complications data.

While only 6.2 per cent of women undergoing mastectomy reported severe pain in the first 24 hours following surgery, 16.5 per cent of immediate and 20.1 per cent of delayed reconstruction patients did so. However, all groups of women seemed equally satisfied that the staff treating them had done everything they could to control their pain.

Following their discharge home, one in ten mastectomy patients and almost one in six reconstruction patients was readmitted for unplanned further treatment or surgery. One in five mastectomy patients and one in four reconstruction patients required antibiotic treatment for a wound infection. One in two mastectomy patients (with or without immediate reconstruction) and a third of all delayed reconstruction patients required aspiration or drainage of a collection of fluid at their operative site.

Overall, nine out of ten women felt that they had received the right amount of information about their chosen procedure. Only half were very satisfied with the information on what their scars would look like and what level of postoperative pain to expect. Just two-thirds of mastectomy only patients reported discussing their surgery with a clinician compared to almost all reconstruction patients. Only one-quarter of those who underwent mastectomy alone were shown photographs of the likely results of their surgery; this compared to eight in ten reconstruction patients. Only 65 per cent of women who had a mastectomy only felt that they had received the right amount of reconstructive information;

42 per cent reported that the lack of information contributed to them not having immediate reconstruction. Women who felt that they did not receive the right amount of reconstructive information were much less likely to have received information in each format.

Overall, 90 per cent of women rated the care they received as excellent or very good and 88 per cent felt that they had always been treated with respect and dignity. These results compare extremely favourably to the results of the survey of all NHS inpatients.

## Summary of findings from the initial year of the National Mastectomy and Breast Reconstruction Audit, published in the First Annual Report

### Service configuration

- Due to its rising incidence, the number of breast cancer operations performed by the English NHS rose from 24,684 in 1997 to 33,814 in 2006, an increase of 37 per cent.
- Between 1997 and 2006, the proportion of mastectomy patients undergoing immediate reconstruction rose from 7 per cent to 11 per cent.
- Local access to breast reconstruction services is not uniform across England and Wales.

### Communication with patients

- Breast care nurses have a key role in supporting women through the decision about whether or not to have immediate breast reconstruction. Women's access to reconstruction may be impaired by the relatively small number of specialist nurses employed in the English NHS.

### Time to allow informed and reasoned decision making

- To make an informed decision about immediate breast reconstruction, women need enough time to digest the information and choices available. There is a perception that decisions about reconstruction may be rushed by the need to provide the first definitive treatment within 31 days of diagnosis.

### Training of staff

- 80 NHS trusts reported that pedicle flap breast reconstructions were being performed by general surgeons with a specialty interest in breast surgery. However, breast reconstruction surgery is still being performed at a number of NHS trusts with relatively little experience in this area. These units provide a poor environment in which to train and improve reconstructive skills.

### Communication between clinicians

- 94 per cent of private hospitals reported that their breast cancer surgery patients are discussed by a multi-disciplinary team elsewhere. This may impair the quality and timeliness of reconstructive decision making for these patients.

## Summary of findings from the Second Annual Report of the National Mastectomy and Breast Reconstruction Audit

### Patterns of surgical care

- The most common type of procedure for women undergoing immediate reconstruction was an implant or tissue expander based reconstruction (38 per cent). For women undergoing delayed reconstruction, the most common type was free flap reconstruction (33 per cent). This may reflect difficulties in access to a specialist reconstructive team while meeting the target of starting definitive treatment within 31 days of decision to treat.

### Time from decision to treat to first definitive treatment

- The time from decision to treat to first definitive surgical treatment varied between Cancer Networks. The proportion of women treated within 31 days varied from 76 per cent to 94 per cent for women having mastectomy only, and from 28 per cent to 84 per cent for women having mastectomy with immediate reconstruction. Poorer levels of performance may reflect variable resources and capacity at breast units in England.

### Reconstructive offer and uptake across English Cancer Networks

- Among the 15,479 women who underwent mastectomy, 3,216 (21 per cent) underwent immediate breast reconstruction.
- Rates of immediate reconstruction varied significantly from 9 per cent to 43 per cent between the 30 English Cancer Networks (p-value<0.001). This variation was not explained by the socio-demographic and clinical characteristics of the women treated.
- The proportion of women offered immediate reconstruction varied significantly between Networks (p-value<0.001). Again, this variation was not explained by patient characteristics or planned clinical treatment. Moreover, offer rates were not strongly correlated with actual rates of reconstruction in the Cancer Networks.
- The reasons given by clinicians for not offering women immediate reconstruction were: women were deemed inappropriate for clinical, health or lifestyle problems, or a perceived need for adjuvant radiotherapy.

### Postoperative outcomes of surgery

- Mastectomy and breast reconstruction are safe procedures, with a very low incidence of mortality (<0.3 per cent) or complications requiring emergency transfer to intensive or high-dependency care (<1 per cent).
- The total flap failure rate for free flap reconstructions was 1.95 per cent (95 per cent confidence intervals 1.08 to 2.82); the partial flap failure rate was 2.46 per cent (95 per cent confidence intervals 1.49 to 3.44).

## Summary of findings from the Third Annual Report of the National Mastectomy and Breast Reconstruction Audit

### Postoperative outcomes of surgery

- Around 10 per cent of women undergoing mastectomy had a local complication.
- The proportion of mastectomy only and immediate reconstruction patients who had at least one complication ranged from 15 per cent to 18 per cent for different procedures.
- Pedicle flap reconstructions involved an increased risk of flap donor site haematoma and seroma.
- Free-flap reconstructions involved an increased risk of re-examination in theatre.

### Outcomes across NHS trusts and independent hospitals

- Funnel plots of the case-mix and procedure adjusted rates for return to theatre, mastectomy-site complications and distant/systemic complications showed that trust and hospital-level rates did not differ significantly from the national rate.
- However, 50 organisations were excluded from this comparative analysis due to low case-ascertainment or incomplete complications data.

### Postoperative pain and its management

- 16.5 per cent of immediate and 20.1 per cent of delayed reconstruction patients reported severe pain in the first 24 hours following surgery, while only 6.2 per cent of women undergoing mastectomy did so.
- However, all groups of women seemed equally satisfied that the staff treating them had done everything they could to control their pain.

### Post-discharge complications and sequelae

- One in ten mastectomy patients and almost one in six reconstruction patients was readmitted for unplanned further treatment or surgery.
- One in five mastectomy patients and one in four reconstruction patients required antibiotic treatment for a wound infection.
- One in two mastectomy patients (with or without immediate reconstruction) and a third of all delayed reconstruction patients required aspiration or drainage of a collection of fluid at their operative site.

### Information provided prior to surgery

- Overall, nine out of ten women felt that they had received the right amount of information about their chosen procedure.
- Only half were very satisfied with the information on what their scars would look like and what level of postoperative pain to expect.
- Just two-thirds of mastectomy only patients reported discussing their surgery with a clinician compared to almost all reconstruction patients.
- Only one-quarter of those who underwent mastectomy alone were shown photographs of the likely results compared to eight in ten reconstruction patients.
- Only 65 per cent of women who had a mastectomy only felt that they had received the right amount of reconstructive information; 42 per cent reported that the lack of information contributed to them not having immediate reconstruction.
- Women who felt that they did not receive the right amount of reconstructive information were much less likely to have received information in each format.

### Overall experience of care

- 90 per cent of women rated the care they received as excellent or very good.
- 88 per cent felt that they had always been treated with respect and dignity.

## Appendix 2: Organisational representatives

### National Mastectomy and Breast Reconstruction Audit Project Board

Julie Henderson**	Project Board Executive	The NHS Information Centre for health and social care
Jan van der Meulen	Senior Supplier	Clinical Effectiveness Unit, The Royal College of Surgeons of England
Steve Dean	Senior Supplier	National Clinical Audit Support Programme, The NHS Information Centre for health and social care
Hugh Bishop	Senior User	Association of Breast Surgery at BASO
Venkat Ramakrishnan	Senior User	British Association of Plastic, Reconstructive and Aesthetic Surgeons
Helen Laing	Commissioner	Healthcare Quality Improvement Partnership

\*\* replaced Martin Old, formerly of The NHS Information Centre for health and social care

### Clinical Reference Group

Dick Rainsbury, Chair	Association of Breast Surgery at BASO
Chris Holcombe	Association of Breast Surgery at BASO
Emma Pennary	Breast Cancer Care
Elaine Sassoon	British Association of Plastic, Reconstructive and Aesthetic Surgeons
Eva Weiler-Mithoff	British Association of Plastic, Reconstructive and Aesthetic Surgeons
Di Riley	Cancer Action Team
Lucy Elliss-Brookes	Cancer Networks
Gillian Ross	Faculty of Clinical Oncology
Judi Ingram	Independent sector
Bethan Lloyd Owen	Independent sector
Catherine Boyle	Macmillan Cancer Support
Christianne Forrest	Patient representative, Breast Cancer Voices
Kate Jones	The Chartered Society of Physiotherapists
Helen Mcleod	The Chartered Society of Physiotherapists
Peter Venn	The Royal College of Anaesthetists
Maria Noblet	The Royal College of Nursing
Janet Litherland	The Royal College of Radiologists
Gill Lawrence	United Kingdom Association of Cancer Registries
Ian Monypenny	Cancer Services Co-ordinating Group, Wales

Dr Karen Woo was a member of the Clinical Reference Group before her untimely death in Afghanistan in August 2010.

## Appendix 3: NHS trust and independent hospital participation

English NHS Trusts				
Organisation Name	Number of women registered	Number with complete operative data	Estimated case ascertainment (%)	Percentage of eligible women asked for PROMs consent
Aintree University Hospitals NHS Foundation Trust	96	93	75 to 100	98
Airedale NHS Trust	81	79	75 to 100	93
Ashford and St Peter's Hospitals NHS Trust	78	66	50 to 75	61
Barking, Havering and Redbridge Hospitals NHS Trust	154	146	75 to 100	73
Barnet and Chase Farm Hospitals NHS Trust	86	85	50 to 75	100
Barnsley Hospital NHS Foundation Trust	62	57	50 to 75	98
Barts and The London NHS Trust	127	118	75 to 100	75
Basildon and Thurrock University Hospitals NHS Foundation Trust	26	26	50 to 75	100
Basingstoke and North Hampshire NHS Foundation Trust	49	43	50 to 75	0
Bedford Hospital NHS Trust	65	64	75 to 100	36
Blackpool, Fylde and Wyre Hospitals NHS Trust	131	131	75 to 100	44
Royal Bolton Hospital NHS Foundation Trust	199	197	75 to 100	84
Bradford Teaching Hospitals NHS Foundation Trust	205	175	75 to 100	83
Brighton and Sussex University Hospitals NHS Trust	117	117	75 to 100	2
Bromley Hospitals NHS Trust	116	114	75 to 100	92
Buckinghamshire Hospitals NHS Trust	134	133	75 to 100	40
Burton Hospitals NHS Trust	61	61	75 to 100	13
Calderdale And Huddersfield NHS Foundation Trust	144	129	75 to 100	98
Cambridge University Hospitals NHS Foundation Trust	205	205	75 to 100	85
Chelsea and Westminster Healthcare NHS Trust	3	3	75 to 100	100
Chesterfield Royal Hospital NHS Foundation Trust	178	162	75 to 100	33
The Christie NHS Foundation Trust	48	47	75 to 100	77
City Hospitals Sunderland NHS Foundation Trust	77	43	50 to 75	31
Countess of Chester Hospital NHS Foundation Trust	120	111	50 to 75	88
County Durham and Darlington NHS Foundation Trust	192	192	75 to 100	79
Dartford and Gravesham NHS Trust	67	67	75 to 100	28
Derby Hospitals NHS Foundation Trust	271	270	75 to 100	25
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	203	188	75 to 100	0
Dorset County Hospitals NHS Foundation Trust	64	63	75 to 100	92
Dudley Group of Hospitals NHS Trust	152	146	75 to 100	5
Ealing Hospital NHS Trust	8	8	25 to 50	83
East and North Hertfordshire NHS Trust	7	6	0 to 25	71
East Cheshire NHS Trust	150	136	75 to 100	74
East Kent Hospitals NHS Trust	65	60	25 to 50	40
East Lancashire Hospitals NHS Trust	37	35	0 to 25	97
East Sussex Hospitals NHS Trust	175	174	75 to 100	9
Colchester Hospital University NHS Foundation Trust	54	42	25 to 50	35
Frimley Park Hospital NHS Foundation Trust	118	107	75 to 100	68
Gateshead Health NHS Foundation Trust	117	85	50 to 75	35
George Eliot Hospital NHS Trust	63	63	75 to 100	66
Gloucestershire Hospitals NHS Foundation Trust	146	143	50 to 75	14
Guy's and St Thomas' NHS Foundation Trust	218	213	75 to 100	46
Harrogate and District NHS Foundation Trust	41	31	50 to 75	69
Heart of England NHS Foundation Trust	200	162	50 to 75	65
Heatherwood and Wexham Park Hospitals NHS Trust	94	91	75 to 100	49
Hereford Hospitals NHS Trust	92	90	75 to 100	98
Hinchingbrooke Health Care NHS Trust	20	4	0 to 25	5
Homerton University Hospital NHS Foundation Trust	34	29	75 to 100	100
Hull and East Yorkshire Hospitals NHS Trust	249	241	75 to 100	3
Imperial College Healthcare NHS Trust	144	139	50 to 75	96
Ipswich Hospital NHS Trust	123	122	75 to 100	0
Isle of Wight NHS Primary Care Trust	105	84	75 to 100	17
James Paget University Hospitals NHS Foundation Trust	124	115	75 to 100	97
Medway NHS Foundation Trust	49	47	25 to 50	94
Kettering General Hospital NHS Trust	110	107	75 to 100	90
King's College Hospital NHS Foundation Trust	39	39	75 to 100	0
Kingston Hospital NHS Trust	54	54	50 to 75	35
Lancashire Teaching Hospitals NHS Foundation Trust	123	123	50 to 75	79
Leeds Teaching Hospitals NHS Trust	243	231	75 to 100	84

## English NHS Trusts continued

Organisation Name	Number of women registered	Number with complete operative data	Estimated case ascertainment (%)	Percentage of eligible women asked for PROMs consent
Liverpool Women's NHS Foundation Trust	47	47	75 to 100	41
Luton and Dunstable Hospital NHS Trust	10	10	0 to 25	100
Maidstone and Tunbridge Wells NHS Trust	99	99	75 to 100	90
Mayday Healthcare NHS Trust	94	83	75 to 100	80
Mid Essex Hospital Services NHS Trust	233	231	75 to 100	73
Mid Staffordshire General Hospitals NHS Trust	9	2	0 to 25	100
Mid Yorkshire Hospitals NHS Trust	225	222	75 to 100	30
Milton Keynes General Hospital NHS Trust	43	40	50 to 75	2
Newham University Hospital NHS Trust	26	26	50 to 75	96
Norfolk and Norwich University Hospital NHS Trust	301	301	75 to 100	45
North Bristol NHS Trust	184	181	75 to 100	82
Warrington and Halton Hospitals NHS Foundation Trust	86	83	75 to 100	7
North Cumbria Acute Hospitals NHS Trust	133	133	75 to 100	99
North Middlesex University Hospital NHS Trust	3	0	0 to 25	100
North Tees and Hartlepool NHS Foundation Trust	200	195	75 to 100	59
North West London Hospitals NHS Trust	90	55	50 to 75	52
Northampton General Hospital NHS Trust	49	14	0 to 25	71
Northern Devon Healthcare NHS Trust	47	45	75 to 100	98
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	40	37	25 to 50	100
Northumbria Healthcare NHS Foundation Trust	111	108	50 to 75	98
Nottingham University Hospitals NHS Trust	293	290	75 to 100	19
Oxford Radcliffe Hospitals NHS Trust	186	175	50 to 75	94
Pennine Acute Hospitals NHS Trust	243	234	75 to 100	46
Peterborough and Stamford Hospitals NHS Foundation Trust	136	136	75 to 100	28
Plymouth Hospitals NHS Trust	219	216	75 to 100	22
Poole Hospital NHS Foundation Trust	83	81	75 to 100	90
Portsmouth Hospitals NHS Trust	221	175	75 to 100	71
Queen Elizabeth Hospital NHS Trust	45	45	50 to 75	2
Queen Mary's Sidcup NHS Trust	46	44	75 to 100	13
Queen Victoria Hospital NHS Foundation Trust	121	121	75 to 100	98
Royal Berkshire NHS Foundation Trust	121	105	75 to 100	34
Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	96	94	75 to 100	88
Royal Cornwall Hospitals NHS Trust	174	171	75 to 100	17
Royal Devon and Exeter NHS Foundation Trust	160	150	50 to 75	69
Royal Free Hampstead NHS Trust	133	111	50 to 75	23
Royal Liverpool and Broadgreen University Hospitals NHS Trust	169	168	75 to 100	49
Royal Surrey County Hospital NHS Trust	80	80	75 to 100	64
Royal United Hospital Bath NHS Trust	132	131	75 to 100	99
Royal West Sussex NHS Trust	65	64	75 to 100	74
Salford Royal Hospitals NHS Foundation Trust	90	89	75 to 100	97
Salisbury NHS Foundation Trust	179	173	75 to 100	40
Sandwell and West Birmingham Hospitals NHS Trust	199	189	75 to 100	90
Scarborough and North East Yorkshire Healthcare NHS Trust	25	24	75 to 100	100
Sheffield Teaching Hospitals NHS Foundation Trust	210	196	75 to 100	54
Sherwood Forest Hospitals NHS Foundation Trust	138	136	75 to 100	87
South Devon Healthcare NHS Foundation Trust	116	116	75 to 100	92
University Hospital of South Manchester NHS Foundation Trust	204	202	50 to 75	0
South Tees Hospitals NHS Trust	192	189	75 to 100	25
South Tyneside NHS Foundation Trust	51	51	75 to 100	96
South Warwickshire General Hospitals NHS Trust	76	76	50 to 75	100
Southampton University Hospitals NHS Trust	155	149	75 to 100	6
Southend Hospital NHS Trust	95	94	75 to 100	7
Southport and Ormskirk Hospital NHS Trust	35	32	50 to 75	14
St George's Healthcare NHS Trust	83	70	50 to 75	58
St Helens and Knowsley Hospitals NHS Trust	117	115	75 to 100	63
Stockport NHS Foundation Trust	70	68	75 to 100	73
Surrey and Sussex Healthcare NHS Trust	87	86	75 to 100	100
Great Western Hospitals NHS Foundation Trust	92	92	75 to 100	98
Tameside Hospital NHS Foundation Trust	51	50	75 to 100	88



English NHS Trusts continued

Organisation Name	Number of women registered	Number with complete operative data	Estimated case ascertainment (%)	Percentage of eligible women asked for PROMs consent
Taunton and Somerset NHS Trust	120	114	75 to 100	70
The Hillingdon Hospital NHS Trust	61	61	75 to 100	100
The Mid Cheshire Hospitals NHS Trust	99	98	75 to 100	91
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	321	318	75 to 100	90
The Princess Alexandra Hospital NHS Trust	107	107	75 to 100	99
The Queen Elizabeth Hospital King's Lynn NHS Trust	104	104	75 to 100	100
The Rotherham NHS Foundation Trust	81	81	75 to 100	99
The Royal Marsden NHS Foundation Trust	351	347	75 to 100	6
The Royal Wolverhampton Hospitals NHS Trust	96	95	75 to 100	66
The Shrewsbury and Telford Hospital NHS Trust	147	147	75 to 100	97
The Whittington Hospital NHS Trust	32	17	50 to 75	78
University Hospitals Bristol NHS Foundation Trust	99	97	75 to 100	68
United Lincolnshire Hospitals NHS Trust	190	188	50 to 75	29
University College London Hospitals NHS Foundation Trust	32	8	0 to 25	0
University Hospital Birmingham NHS Foundation Trust	119	100	50 to 75	75
University Hospital of North Staffordshire NHS Trust	63	59	25 to 50	16
University Hospitals Coventry and Warwickshire NHS Trust	150	150	75 to 100	97
University Hospitals of Leicester NHS Trust	302	287	75 to 100	70
University Hospitals of Morecambe Bay NHS Trust	133	132	25 to 50	23
Walsall Hospitals NHS Trust	96	96	75 to 100	33
West Hertfordshire Hospitals NHS Trust	116	115	75 to 100	58
West Middlesex University Hospital NHS Trust	36	36	75 to 100	94
West Suffolk Hospitals NHS Trust	94	94	75 to 100	81
Weston Area Health NHS Trust	55	55	75 to 100	91
Whipps Cross University Hospital NHS Trust	60	59	75 to 100	42
Winchester and Eastleigh Healthcare NHS Trust	85	84	75 to 100	64
Wirral University Teaching Hospital NHS Foundation Trust	88	77	75 to 100	43
Worcestershire Acute Hospitals NHS Trust	172	171	75 to 100	42
Worthing and Southlands Hospitals NHS Trust	118	118	75 to 100	99
Wrightington, Wigan and Leigh NHS Trust	207	114	50 to 75	100
Yeovil District Hospital NHS Foundation Trust	51	51	75 to 100	94
York Hospitals NHS Foundation Trust	169	166	75 to 100	96

Independent hospitals				
Organisation Name	Number of women registered	Number with complete operative data	Estimated case ascertainment (%)	Percentage of eligible women asked for PROMs consent
BMI Bath Clinic	20	19	75 to 100	100
BMI Bishops Wood Hospital	2	0	0 to 25	100
BMI Chatsworth Suite	2	1	0 to 25	50
BMI Chelsfield Park Hospital	6	5	50 to 75	100
BMI Fawkham Manor Hospital	4	4	75 to 100	100
BMI Goring Hall Hospital	7	0	0 to 25	0
BMI Mount Alvernia Hospital	32	32	50 to 75	100
BMI Priory Hospital	36	34	50 to 75	100
BMI Sarum Road Hospital	13	13	50 to 75	100
BMI The Alexandra Hospital	4	4	0 to 25	0
BMI The Beaumont Hospital	8	8	50 to 75	100
BMI The Blackheath Hospital	3	3	25 to 50	100
BMI The Cavell Hospital	9	8	Unknown	100
BMI The Chaucer Hospital	11	11	25 to 50	0
BMI The Chiltern Hospital	28	28	75 to 100	86
BMI The Clementine Churchill Hospital	10	2	0 to 25	0
BMI The Droitwich Spa Hospital	7	6	50 to 75	100
BMI The Esperance Hospital	13	12	50 to 75	0
BMI The Foscote Hospital	1	1	0 to 25	0
BMI The Hampshire Clinic	15	13	25 to 50	0
BMI The Harbour Hospital	16	7	25 to 50	100
BMI The Highfield Hospital	1	0	0 to 25	100
BMI The Kings Oak Hospital	12	8	50 to 75	100
BMI The Lincoln Hospital	1	1	Unknown	0
BMI The Manor Hospital	8	8	50 to 75	13
BMI The Park Hospital	63	55	50 to 75	83
BMI The Princess Margaret	32	30	75 to 100	100
BMI The Ridgeway Hospital	5	4	0 to 25	100
BMI The Sandringham Hospital	4	4	25 to 50	100
BMI The Saxon Clinic	11	11	25 to 50	100
BMI The Shelburne Hospital	9	9	50 to 75	100
BMI The Sloane Hospital	17	17	50 to 75	82
BMI The Somerfield Hospital	24	21	25 to 50	100
BMI The Winterbourne Hospital	2	2	50 to 75	50
BMI Thornbury Hospital	11	1	0 to 25	100
BMI Werndale Hospital	6	4	75 to 100	0
BMI Woodlands Hospital	3	3	75 to 100	0
Cromwell Hospital	22	21	Unknown	100
HCA Lister Hospital	1	1	0 to 25	100
HCA London Bridge Hospital	21	16	75 to 100	0
HCA The Harley Street Clinic	15	10	25 to 50	7
HCA The Princess Grace Hospital	86	84	75 to 100	82
Hospital of St John & St Elizabeth	16	10	Unknown	94
Nuffield Health Bournemouth Hospital	2	0	0 to 25	100
Nuffield Health Brentwood Hospital	30	22	25 to 50	100
Nuffield Health Brighton Hospital	14	14	50 to 75	100
Nuffield Health Bristol Hospital	1	1	0 to 25	100
Nuffield Health Cambridge Hospital	5	5	75 to 100	100
Nuffield Health Cheltenham Hospital	13	12	50 to 75	100
Nuffield Health Derby Hospital	15	14	75 to 100	40
Nuffield Health Exeter Hospital	7	7	50 to 75	100
Nuffield Health Grosvenor Hospital	7	6	50 to 75	100
Nuffield Health Hereford Hospital	4	4	50 to 75	100
Nuffield Health Hull Hospital	7	7	Unknown	0
Nuffield Health Ipswich Hospital	9	9	75 to 100	100
Nuffield Health Newcastle-upon-Tyne Hospital	10	9	50 to 75	70
Nuffield Health North Staffordshire Hospital	3	3	0 to 25	100
Nuffield Health Plymouth Hospital	6	5	25 to 50	50
Nuffield Health Shrewsbury Hospital	2	2	25 to 50	100

**Independent hospitals continued**

Organisation Name	Number of women registered	Number with complete operative data	Estimated case ascertainment (%)	Percentage of eligible women asked for PROMs consent
Nuffield Health Taunton Hospital	15	15	75 to 100	27
Nuffield Health Tees Hospital	11	3	25 to 50	9
Nuffield Health Tunbridge Wells Hospital	12	12	75 to 100	25
Nuffield Health Wessex Hospital	8	8	75 to 100	0
Nuffield Health Woking Hospital	7	5	50 to 75	100
Nuffield Health Wolverhampton Hospital	3	0	0 to 25	0
Nuffield Health York Hospital	9	9	25 to 50	100
Parkside Hospital	10	10	Unknown	100
Ramsay Ashted Hospital	1	0	0 to 25	0
Ramsay Duchy Hospital	1	1	25 to 50	0
Ramsay Euxton Hall Hospital	9	8	25 to 50	100
Ramsay Fitzwilliam Hospital	8	7	50 to 75	50
Ramsay Mount Stuart Hospital	2	2	25 to 50	50
Ramsay New Hall Hospital	6	6	25 to 50	0
Ramsay Oaks Hospital	1	0	0 to 25	100
Ramsay Park Hill Hospital	3	3	50 to 75	0
Ramsay Rivers Hospital	11	11	50 to 75	100
Ramsay Rowley Hospital	1	1	0 to 25	0
Ramsay Springfield Hospital	21	17	25 to 50	95
Ramsay Yorkshire Clinic	20	15	25 to 50	0
Ramsay West Midlands Hospital	18	10	25 to 50	100
Spire Alexandra Hospital	5	5	50 to 75	100
Spire Bristol Hospital	34	29	50 to 75	100
Spire Bushey Hospital	18	9	25 to 50	100
Spire Cambridge Lea Hospital	17	17	50 to 75	100
Spire Cheshire Hospital	9	9	50 to 75	0
Spire Clare Park Hospital	12	8	25 to 50	33
Spire Dunedin Hospital	22	20	50 to 75	0
Spire Elland Hospital	10	9	50 to 75	100
Spire Gatwick Park Hospital	22	18	50 to 75	0
Spire Harpenden Hospital	2	1	0 to 25	100
Spire Hartswood Hospital	7	7	50 to 75	14
Spire Hull and East Riding Hospital	5	3	25 to 50	40
Spire Leeds Hospital	27	24	25 to 50	100
Spire Little Aston Hospital	33	30	75 to 100	52
Spire Liverpool Hospital	3	2	25 to 50	67
Spire Manchester Hospital	25	25	25 to 50	0
Spire Methley Park Hospital	6	5	25 to 50	100
Spire Murrayfield Hospital Wirral	13	12	50 to 75	62
Spire Norwich Hospital	25	22	50 to 75	80
Spire Parkway Hospital	23	21	50 to 75	64
Spire Portsmouth Hospital	7	6	25 to 50	0
Spire Regency Hospital	5	4	50 to 75	0
Spire Roding Hospital	4	4	25 to 50	0
Spire South Bank Hospital	5	5	50 to 75	100
Spire Southampton Hospital	19	19	75 to 100	95
Spire St Saviour's Hospital	8	7	75 to 100	0
Spire Sussex Hospital	2	2	50 to 75	0
Spire Thames Valley Hospital	15	15	75 to 100	67
Spire Tunbridge Wells Hospital	3	2	25 to 50	100
Spire Washington Hospital	7	7	50 to 75	100
Spire Wellesley Hospital	5	5	50 to 75	100
St Josephs Private Hospital	11	11	Unknown	100
The London Clinic	93	89	Unknown	0
The New Victoria Hospital	4	3	Unknown	50

Non-English NHS Trusts				
Organisation Name	Number of women registered	Number with complete operative data	Estimated case ascertainment (%)	Percentage of eligible women asked for PROMs consent
Cwm Taf NHS Trust	19	18	Unknown	100
Abertawe Bro Morgannwg University NHS Trust	4	4	Unknown	100
North West Wales NHS Trust	116	112	Unknown	97
Cardiff and Vale NHS Trust	25	25	Unknown	100
Gwent Healthcare NHS Trust	109	107	Unknown	99
NHS Grampian	143	143	Unknown	1

## Appendix 4: Organisational adjusted mean scores for scales contained in the 3 month questionnaire

Organisations at which no registered patients were asked to participate in the PROMS study

### English NHS trusts

- Basingstoke and North Hampshire NHS Foundation Trust
- Doncaster and Bassetlaw Hospitals NHS Foundation Trust
- Ipswich Hospital NHS Trust
- King's College Hospital NHS Foundation Trust
- University Hospital of South Manchester NHS Foundation Trust
- University College London Hospitals NHS Foundation Trust

### Independent hospitals

- BMI Goring Hall Hospital
- BMI The Alexandra Hospital
- BMI The Chaucer Hospital
- BMI The Clementine Churchill Hospital
- BMI The Esperance Hospital
- BMI The Foscote Hospital
- BMI The Hampshire Clinic
- BMI The Lincoln Hospital
- BMI Werndale Hospital
- BMI Woodlands Hospital
- HCA London Bridge Hospital
- Nuffield Health Hull Hospital
- Nuffield Health Wessex Hospital
- Nuffield Health Wolverhampton Hospital
- Ramsay Ashtead Hospital
- Ramsay Duchy Hospital
- Ramsay New Hall Hospital
- Ramsay Park Hill Hospital
- Ramsay Rowley Hospital
- Ramsay Yorkshire Clinic
- Spire Cheshire Hospital
- Spire Dunedin Hospital
- Spire Gatwick Park Hospital
- Spire Manchester Hospital
- Spire Portsmouth Hospital
- Spire Regency Hospital
- Spire Roding Hospital
- Spire St Saviour's Hospital
- Spire Sussex Hospital
- The London Clinic

**Mean adjusted scores for organisations who participated in the PROMS study**

Values are not derived for organisations for which there were fewer than 3 responses. Where this applied to all scores, the row is left blank.

(\*\*) is used when this applied to a single score

Organisation Name	Number of women registered	No. of 3 month questionnaires in analysis	Satisfaction with information provision	Satisfaction with consultant surgeon	Satisfaction with clinical team
Aintree University Hospitals NHS Foundation Trust	96	59	68	89	93
Airedale NHS Trust	81	49	75	93	93
Ashford and St Peter's Hospitals NHS Trust	78	25	67	91	91
Barking, Havering and Redbridge Hospitals NHS Trust	154	68	58	74	81
Barnet and Chase Farm Hospitals NHS Trust	86	28	71	89	89
Barnsley Hospital NHS Foundation Trust	62	49	77	97	91
Barts and The London NHS Trust	127	19	66	87	94
Basildon and Thurrock University Hospitals NHS Foundation Trust	26	16	62	84	94
Bedford Hospital NHS Trust	65	17	64	87	86
Blackpool, Fylde and Wyre Hospitals NHS Trust	131	38	66	80	88
Bradford Teaching Hospitals NHS Foundation Trust	205	59	71	92	95
Brighton and Sussex University Hospitals NHS Trust	117	26	78	85	87
Bromley Hospitals NHS Trust	116	57	67	84	86
Buckinghamshire Hospitals NHS Trust	134	31	74	92	94
Burton Hospitals NHS Trust	61	8	60	74	67
Calderdale and Huddersfield NHS Foundation Trust	144	56	63	81	91
Cambridge University Hospitals NHS Foundation Trust	205	93	73	90	88
Chelsea and Westminster Healthcare NHS Trust	3	3	77	97	63
Chesterfield Royal Hospital NHS Foundation Trust	178	2			
City Hospitals Sunderland NHS Foundation Trust	77	7	84	99	94
Colchester Hospital University NHS Foundation Trust	54	13	75	87	93
Countess of Chester Hospital NHS Foundation Trust	120	45	71	91	88
County Durham and Darlington NHS Foundation Trust	192	72	68	91	89
Dartford and Gravesham NHS Trust	67	16	73	85	90
Derby Hospitals NHS Foundation Trust	271	50	77	94	93
Dorset County Hospitals NHS Foundation Trust	64	44	70	77	89
Dudley Group of Hospitals NHS Trust	152	6	63	90	76
Ealing Hospital NHS Trust	8	3	85	91	91
East and North Hertfordshire NHS Trust	7	5	58	81	75
East Cheshire NHS Trust	150	80	81	94	94
East Kent Hospitals NHS Trust	65	23	68	94	89
East Lancashire Hospitals NHS Trust	37	20	85	97	97
East Sussex Hospitals NHS Trust	175	13	74	86	88
Frimley Park Hospital NHS Foundation Trust	118	63	75	85	93
Gateshead Health NHS Foundation Trust	117	8	68	93	93
George Eliot Hospital NHS Trust	63	29	68	89	91
Gloucestershire Hospitals NHS Foundation Trust	146	15	80	94	99
Great Western Hospitals NHS Foundation Trust	92	49	76	91	95
Guy's and St Thomas' NHS Foundation Trust	218	38	64	86	73
Harrogate and District NHS Foundation Trust	41	12	76	89	86
Heart of England NHS Foundation Trust	200	38	71	87	90
Heatherwood and Wexham Park Hospitals NHS Trust	94	10	81	90	86
Hereford Hospitals NHS Trust	92	56	67	85	88
Hinchingbrooke Health Care NHS Trust	20	2			
Homerton University Hospital NHS Foundation Trust	34	18	71	78	91
Hull and East Yorkshire Hospitals NHS Trust	249	5	84	75	90
Imperial College Healthcare NHS Trust	144	72	67	87	85
Isle of Wight NHS Primary Care Trust	105	12	73	85	94
James Paget University Hospitals NHS Foundation Trust	124	72	70	85	92
Kettering General Hospital NHS Trust	110	79	66	85	96
Kingston Hospital NHS Trust	54	11	70	88	89
Lancashire Teaching Hospitals NHS Foundation Trust	123	30	69	92	96
Leeds Teaching Hospitals NHS Trust	243	148	70	89	92
Liverpool Women's NHS Foundation Trust	47	15	76	94	92
Luton and Dunstable Hospital NHS Trust	10	10	67	88	92
Maidstone and Tunbridge Wells NHS Trust	99	57	72	91	89

# Mean adjusted scores for organisations who participated in the PROMS study continued

Values are not derived for organisations for which there were fewer than 3 responses. Where this applied to all scores, the row is left blank.

(\*\*) is used when this applied to a single score

Organisation Name	Number of women registered	No. of 3 month questionnaires in analysis	Satisfaction with information provision	Satisfaction with consultant surgeon	Satisfaction with clinical team
Mayday Healthcare NHS Trust	94	41	73	86	79
Medway NHS Foundation Trust	49	20	62	76	83
Mid Essex Hospital Services NHS Trust	233	131	70	88	93
Mid Staffordshire General Hospitals NHS Trust	9	1			
Mid Yorkshire Hospitals NHS Trust	225	51	71	88	86
Milton Keynes General Hospital NHS Trust	43	2			
Newham University Hospital NHS Trust	26	11	62	82	80
Norfolk and Norwich University Hospital NHS Trust	301	106	76	92	93
North Bristol NHS Trust	184	116	69	90	88
North Cumbria Acute Hospitals NHS Trust	133	99	76	89	92
North Middlesex University Hospital NHS Trust	3	1			
North Tees and Hartlepool NHS Foundation Trust	200	79	71	90	93
North West London Hospitals NHS Trust	90	10	66	86	100
Northampton General Hospital NHS Trust	49	26	67	80	88
Northern Devon Healthcare NHS Trust	47	16	79	86	94
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	40	23	71	89	94
Northumbria Healthcare NHS Foundation Trust	111	63	77	90	92
Nottingham University Hospitals NHS Trust	293	46	74	88	86
Oxford Radcliffe Hospitals NHS Trust	186	75	75	88	94
Pennine Acute Hospitals NHS Trust	243	61	71	88	88
Peterborough and Stamford Hospitals NHS Foundation Trust	136	25	76	86	90
Plymouth Hospitals NHS Trust	219	21	75	93	89
Poole Hospital NHS Foundation Trust	83	44	72	80	86
Portsmouth Hospitals NHS Trust	221	114	71	88	93
Queen Elizabeth Hospital NHS Trust	45	No questionnaires returned from consenting patients			
Queen Mary's Sidcup NHS Trust	46	6	76	87	88
Queen Victoria Hospital NHS Foundation Trust	121	72	78	93	92
Royal Berkshire NHS Foundation Trust	121	27	75	88	93
Royal Bolton Hospital NHS Foundation Trust	199	116	74	89	91
Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	96	37	65	86	86
Royal Cornwall Hospitals NHS Trust	174	17	69	94	97
Royal Devon and Exeter NHS Foundation Trust	160	65	77	95	92
Royal Free Hampstead NHS Trust	133	9	72	94	88
Royal Liverpool and Broadgreen University Hospitals NHS Trust	169	50	77	94	95
Royal Surrey County Hospital NHS Trust	80	19	72	80	89
Royal United Hospital Bath NHS Trust	132	104	78	90	94
Royal West Sussex NHS Trust	65	30	71	87	86
Salford Royal Hospitals NHS Foundation Trust	90	40	73	93	94
Salisbury NHS Foundation Trust	179	51	67	84	90
Sandwell and West Birmingham Hospitals NHS Trust	199	123	75	93	95
Scarborough and North East Yorkshire Healthcare NHS Trust	25	10	64	85	81
Sheffield Teaching Hospitals NHS Foundation Trust	210	91	76	93	94
Sherwood Forest Hospitals NHS Foundation Trust	138	83	70	84	91
South Devon Healthcare NHS Foundation Trust	116	77	78	92	95
South Tees Hospitals NHS Trust	192	22	80	89	99
South Tyneside NHS Foundation Trust	51	18	78	95	98
South Warwickshire General Hospitals NHS Trust	76	66	71	87	91
Southampton University Hospitals NHS Trust	155	5	67	90	91
Southend Hospital NHS Trust	95	5	78	92	96
Southport and Ormskirk Hospital NHS Trust	35	1			
St George's Healthcare NHS Trust	83	32	72	91	90
St Helens and Knowsley Hospitals NHS Trust	117	33	74	94	88
Stockport NHS Foundation Trust	70	23	67	87	92
Surrey and Sussex Healthcare NHS Trust	87	5	70	80	94
Tameside Hospital NHS Foundation Trust	51	27	62	83	78
Taunton and Somerset NHS Trust	120	39	71	84	94



# Mean adjusted scores for organisations who participated in the PROMS study continued

Values are not derived for organisations for which there were fewer than 3 responses. Where this applied to all scores, the row is left blank. (\*\*) is used when this applied to a single score

Organisation Name	Number of women registered	No. of 3 month questionnaires in analysis	Satisfaction with information provision	Satisfaction with consultant surgeon	Satisfaction with clinical team
The Christie NHS Foundation Trust	48	15	74	97	95
The Hillingdon Hospital NHS Trust	61	21	74	95	95
The Mid Cheshire Hospitals NHS Trust	99	67	72	90	91
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	321	186	74	89	93
The Princess Alexandra Hospital NHS Trust	107	81	70	86	93
The Queen Elizabeth Hospital King's Lynn NHS Trust	104	71	73	91	92
The Rotherham NHS Foundation Trust	81	52	77	92	94
The Royal Marsden NHS Foundation Trust	351	16	73	91	95
The Royal Wolverhampton Hospitals NHS Trust	96	30	71	90	88
The Shrewsbury and Telford Hospital NHS Trust	147	96	64	84	86
The Whittington Hospital NHS Trust	32	6	68	100	71
United Lincolnshire Hospitals NHS Trust	190	34	79	95	91
University Hospital Birmingham NHS Foundation Trust	119	30	71	85	94
University Hospital of North Staffordshire NHS Trust	63	3	99	78	91
University Hospitals Bristol NHS Foundation Trust	99	46	68	86	95
University Hospitals Coventry and Warwickshire NHS Trust	150	90	74	88	88
University Hospitals of Leicester NHS Trust	302	165	69	88	94
University Hospitals of Morecambe Bay NHS Trust	133	43	85	97	97
Walsall Hospitals NHS Trust	96	27	78	91	94
Warrington and Halton Hospitals NHS Foundation Trust	86	No questionnaires returned from consenting patients			
West Hertfordshire Hospitals NHS Trust	116	55	63	82	83
West Middlesex University Hospital NHS Trust	36	17	70	92	86
West Suffolk Hospitals NHS Trust	94	57	71	82	87
Weston Area Health NHS Trust	55	27	73	88	92
Whipps Cross University Hospital NHS Trust	60	13	73	84	89
Winchester and Eastleigh Healthcare NHS Trust	85	43	73	91	95
Wirral University Teaching Hospital NHS Foundation Trust	88	7	79	82	88
Worcestershire Acute Hospitals NHS Trust	172	48	73	96	87
Worthing and Southlands Hospitals NHS Trust	118	77	69	85	89
Wrightington, Wigan and Leigh NHS Trust	207	No questionnaires returned from consenting patients			
Yeovil District Hospital NHS Foundation Trust	51	32	71	84	93
York Hospitals NHS Foundation Trust	169	137	77	95	95

Independent hospitals					
Organisation Name	Number of women registered	No. of 3 month questionnaires in analysis	Satisfaction with information provision	Satisfaction with consultant surgeon	Satisfaction with clinical team
BMI Bath Clinic	20	12	78	95	97
BMI Bishops Wood Hospital	2	2			
BMI Chatsworth Suite	2	No questionnaires returned from consenting patients			
BMI Chelsfield Park Hospital	6	2			
BMI Fawkham Manor Hospital	4	3	77	95	99
BMI Mount Alvernia Hospital	32	18	76	88	95
BMI Priory Hospital	36	21	76	89	91
BMI Sarum Road Hospital	13	5	62	93	95
BMI The Beaumont Hospital	8	6	81	91	96
BMI The Blackheath Hospital	3	No questionnaires returned from consenting patients			
BMI The Cavell Hospital	9	No questionnaires returned from consenting patients			
BMI The Chiltern Hospital	28	16	73	93	96
BMI The Droitwich Spa Hospital	7	4	68	90	97
BMI The Harbour Hospital	16	3	51	85	95
BMI The Highfield Hospital	1	No questionnaires returned from consenting patients			
BMI The Kings Oak Hospital	12	3	69	98	96
BMI The Manor Hospital	8	1			
BMI The Park Hospital	63	No questionnaires returned from consenting patients			
BMI The Princess Margaret	32	20	74	92	94
BMI The Ridgeway Hospital	5	No questionnaires returned from consenting patients			
BMI The Sandringham Hospital	4	4	86	96	100
BMI The Saxon Clinic	11	10	73	91	95
BMI The Shelburne Hospital	9	7	69	93	98
BMI The Sloane Hospital	17	10	74	88	96
BMI The Somerfield Hospital	24	18	82	97	94
BMI The Winterbourne Hospital	2	1			
BMI Thornbury Hospital	11	6	77	98	95
Cromwell Hospital	22	11	75	95	91
Hospital of St John & St Elizabeth	16	3	**	95	87
Lister Hospital	1	No questionnaires returned from consenting patients			
Nuffield Health Bournemouth Hospital	2	1			
Nuffield Health Brentwood Hospital	30	12	74	92	100
Nuffield Health Brighton Hospital	14	3	87	93	88
Nuffield Health Bristol Hospital	1	1			
Nuffield Health Cambridge Hospital	5	3	65	92	100
Nuffield Health Cheltenham Hospital	13	13	71	93	89
Nuffield Health Derby Hospital	15	No questionnaires returned from consenting patients			
Nuffield Health Exeter Hospital	7	3	77	100	86
Nuffield Health Grosvenor Hospital	7	5	75	92	97
Nuffield Health Hereford Hospital	4	2			
Nuffield Health Ipswich Hospital	9	3	54	70	66
Nuffield Health Newcastle-upon-Tyne Hospital	10	1			
Nuffield Health North Staffordshire Hospital	3	3	69	100	96
Nuffield Health Plymouth Hospital	6	2			
Nuffield Health Shrewsbury Hospital	2	2			
Nuffield Health Taunton Hospital	15	1			
Nuffield Health Tees Hospital	11	1			
Nuffield Health Tunbridge Wells Hospital	12	3	72	100	86
Nuffield Health Woking Hospital	7	5	68	97	95
Nuffield Health York Hospital	9	6	80	90	97
Parkside Hospital	10	7	71	99	91
Ramsay Euxton Hall Hospital	9	6	74	83	96
Ramsay Fitzwilliam Hospital	8	2			
Ramsay Mount Stuart Hospital	2	No questionnaires returned from consenting patients			
Ramsay Oaks Hospital	1	No questionnaires returned from consenting patients			
Ramsay Rivers Hospital	11	1			
Ramsay Springfield Hospital	21	7	75	94	87
Ramsay West Midlands Hospital	18	9	68	93	98
Spire Alexandra Hospital	5	3	67	80	100

### Independent hospitals continued

Organisation Name	Number of women registered	No. of 3 month questionnaires in analysis	Satisfaction with information provision	Satisfaction with consultant surgeon	Satisfaction with clinical team
Spire Bristol Hospital	34	22	69	83	93
Spire Bushey Hospital	18	7	87	100	100
Spire Cambridge Lea Hospital	17	10	75	95	95
Spire Clare Park Hospital	12	1			
Spire Elland Hospital	10	9	68	86	96
Spire Harpenden Hospital	2	2			
Spire Hartwood Hospital	7	No questionnaires returned from consenting patients			
Spire Hull and East Riding Hospital	5	No questionnaires returned from consenting patients			
Spire Leeds Hospital	27	15	80	95	100
Spire Little Aston Hospital	33	14	79	88	95
Spire Liverpool Hospital	3	2			
Spire Methley Park Hospital	6	1			
Spire Murrayfield Hospital Wirral	13	5	81	94	100
Spire Norwich Hospital	25	13	80	92	93
Spire Parkway Hospital	23	7	86	99	99
Spire South Bank Hospital	5	4	81	100	100
Spire Southampton Hospital	19	13	65	87	89
Spire Thames Valley Hospital	15	4	62	98	100
Spire Tunbridge Wells Hospital	3	2			
Spire Washington Hospital	7	1			
Spire Wellesley Hospital	5	2			
St Josephs Private Hospital	11	6	86	91	100
The Harley Street Clinic	15	No questionnaires returned from consenting patients			
The New Victoria Hospital	4	1			
The Princess Grace Hospital	86	36	73	92	92

### Non-English NHS trusts

Organisation Name	Number of women registered	No. of 3 month questionnaires in analysis	Satisfaction with information provision	Satisfaction with consultant surgeon	Satisfaction with clinical team
Abertawe Bro Morgannwg University NHS Trust	4	4	60	81	73
Gwent Healthcare NHS Trust	109	91	77	90	90
Cardiff and Vale NHS Trust	25	22	73	86	89
Cwm Taf NHS Trust	19	14	74	93	100
NHS Grampian	143	No questionnaires returned from consenting patients			
North West Wales NHS Trust	116	83	76	91	93

# Appendix 5: Organisational adjusted mean scores for scales contained in the 18 month questionnaire

## Mean adjusted scores for organisations who participated in the PROMS study

Values are not derived for organisations for which there were fewer than 3 responses. Where this applied to all scores, the row is left blank.

(\*\*) is used when this applied to a single score

Organisational name	No. of 18 month questionnaires in analysis	Satisfaction with breast area appearance	Physical well being	Emotional well being	Sexual well being
Aintree University Hospitals NHS Foundation Trust	64	60	75	64	44
Airedale NHS Trust	44	59	76	65	44
Ashford and St Peter's Hospitals NHS Trust	29	54	75	60	53
Barking, Havering and Redbridge Hospitals NHS Trust	62	58	73	63	41
Barnet and Chase Farm Hospitals NHS Trust	25	54	75	63	44
Barnsley Hospital NHS Foundation Trust	42	61	72	71	53
Barts and The London NHS Trust	25	57	75	67	50
Basildon and Thurrock University Hospitals NHS Foundation Trust	16	55	71	65	37
Bedford Hospital NHS Trust	15	56	71	66	57
Blackpool, Fylde and Wyre Hospitals NHS Trust	41	53	71	58	42
Bradford Teaching Hospitals NHS Foundation Trust	56	60	77	68	40
Brighton and Sussex University Hospitals NHS Trust	25	63	73	70	38
Bromley Hospitals NHS Trust	69	53	72	60	35
Buckinghamshire Hospitals NHS Trust	38	64	78	73	51
Burton Hospitals NHS Trust	6	54	71	57	41
Calderdale And Huddersfield NHS Foundation Trust	57	57	76	65	46
Cambridge University Hospitals NHS Foundation Trust	124	61	74	68	46
Chelsea and Westminster Healthcare NHS Trust	2				
Chesterfield Royal Hospital NHS Foundation Trust	2				
City Hospitals Sunderland NHS Foundation Trust	5	67	76	66	49
Colchester Hospital University NHS Foundation Trust	12	61	78	59	32
Countess of Chester Hospital NHS Foundation Trust	43	52	74	59	37
County Durham and Darlington NHS Foundation Trust	76	57	73	66	40
Dartford and Gravesham NHS Trust	17	53	72	63	41
Derby Hospitals NHS Foundation Trust	45	56	74	67	43
Dorset County Hospitals NHS Foundation Trust	46	54	73	62	41
Dudley Group of Hospitals NHS Trust	6	59	75	57	53
Ealing Hospital NHS Trust	2				
East and North Hertfordshire NHS Trust	5	64	80	57	44
East Cheshire NHS Trust	85	62	77	68	44
East Kent Hospitals NHS Trust	22	56	70	71	53
East Lancashire Hospitals NHS Trust	20	63	75	69	48
East Sussex Hospitals NHS Trust	11	58	72	67	54
Frimley Park Hospital NHS Foundation Trust	59	53	73	61	42
Gateshead Health NHS Foundation Trust	23	60	74	65	56
George Eliot Hospital NHS Trust	25	58	75	65	40
Gloucestershire Hospitals NHS Foundation Trust	14	63	79	70	49
Great Western Hospitals NHS Foundation Trust	46	60	72	68	40
Guy's and St Thomas' NHS Foundation Trust	59	53	72	64	43
Harrogate and District NHS Foundation Trust	11	71	88	68	52
Heart of England NHS Foundation Trust	64	60	72	64	41
Heatherwood and Wexham Park Hospitals NHS Trust	19	58	73	62	46
Hereford Hospitals NHS Trust	62	59	73	67	47
Hinchingbrooke Health Care NHS Trust	No questionnaires returned from consenting patients				
Homerton University Hospital NHS Foundation Trust	16	60	68	64	48
Hull and East Yorkshire Hospitals NHS Trust	5	71	77	82	**
Imperial College Healthcare NHS Trust	74	57	74	65	44
Isle of Wight NHS Primary Care Trust	11	51	74	63	42
James Paget University Hospitals NHS Foundation Trust	91	58	74	67	47
Kettering General Hospital NHS Trust	71	54	73	65	43
Kingston Hospital NHS Trust	11	64	70	64	55
Lancashire Teaching Hospitals NHS Foundation Trust	31	60	76	65	43
Leeds Teaching Hospitals NHS Trust	166	58	73	64	41
Liverpool Women's NHS Foundation Trust	14	57	73	62	33
Luton and Dunstable Hospital NHS Trust	10	63	77	64	48
Maidstone and Tunbridge Wells NHS Trust	60	59	75	64	45
Mayday Healthcare NHS Trust	52	53	73	61	38
Medway NHS Foundation Trust	20	59	71	68	37

**Mean adjusted scores for organisations who participated in the PROMS study continued**

Values are not derived for organisations for which there were fewer than 3 responses. Where this applied to all scores, the row is left blank.

(\*\*) is used when this applied to a single score

Organisational name	No. of 18 month questionnaires in analysis	Satisfaction with breast area appearance	Physical well being	Emotional well being	Sexual well being
Mid Essex Hospital Services NHS Trust	140	56	75	64	42
Mid Staffordshire General Hospitals NHS Trust	2				
Mid Yorkshire Hospitals NHS Trust	45	52	66	58	35
Newham University Hospital NHS Trust	14	58	68	63	32
Norfolk and Norwich University Hospital NHS Trust	108	59	75	66	48
North Bristol NHS Trust	104	57	75	67	48
North Cumbria Acute Hospitals NHS Trust	95	62	76	67	51
North Middlesex University Hospital NHS Trust	No questionnaires returned from consenting patients				
North Tees and Hartlepool NHS Foundation Trust	85	58	73	68	45
North West London Hospitals NHS Trust	17	54	79	66	47
Northampton General Hospital NHS Trust	21	56	73	64	44
Northern Devon Healthcare NHS Trust	17	57	72	64	49
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	29	58	67	65	49
Northumbria Healthcare NHS Foundation Trust	65	55	73	63	46
Nottingham University Hospitals NHS Trust	48	61	70	68	50
Oxford Radcliffe Hospitals NHS Trust	103	59	75	67	47
Pennine Acute Hospitals NHS Trust	67	59	75	64	42
Peterborough and Stamford Hospitals NHS Foundation Trust	26	59	73	65	43
Plymouth Hospitals NHS Trust	19	59	79	67	55
Poole Hospital NHS Foundation Trust	46	53	71	56	35
Portsmouth Hospitals NHS Trust	112	56	73	64	39
Queen Mary's Sidcup NHS Trust	6	57	68	63	40
Queen Victoria Hospital NHS Foundation Trust	71	65	74	69	51
Royal Berkshire NHS Foundation Trust	27	63	75	68	43
Royal Bolton Hospital NHS Foundation Trust	117	61	76	66	45
Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	63	53	71	62	40
Royal Cornwall Hospitals NHS Trust	22	59	79	68	38
Royal Devon and Exeter NHS Foundation Trust	54	66	72	71	49
Royal Free Hampstead NHS Trust	12	64	80	68	59
Royal Liverpool and Broadgreen University Hospitals NHS Trust	52	57	76	60	39
Royal Surrey County Hospital NHS Trust	27	57	70	60	36
Royal United Hospital Bath NHS Trust	96	60	76	64	43
Royal West Sussex NHS Trust	30	60	77	67	55
Salford Royal Hospitals NHS Foundation Trust	44	54	70	66	42
Salisbury NHS Foundation Trust	59	61	75	71	46
Sandwell and West Birmingham Hospitals NHS Trust	119	61	77	66	46
Scarborough and North East Yorkshire Healthcare NHS Trust	8	79	81	78	**
Sheffield Teaching Hospitals NHS Foundation Trust	79	60	73	66	41
Sherwood Forest Hospitals NHS Foundation Trust	83	62	74	65	43
South Devon Healthcare NHS Foundation Trust	84	62	79	69	47
South Tees Hospitals NHS Trust	19	70	75	79	49
South Tyneside NHS Foundation Trust	20	66	74	77	62
South Warwickshire General Hospitals NHS Trust	59	61	76	66	57
Southampton University Hospitals NHS Trust	6	53	83	72	42
Southend Hospital NHS Trust	7	51	77	64	44
Southport and Ormskirk Hospital NHS Trust	3	51	63	66	**
St George's Healthcare NHS Trust	29	62	72	64	40
St Helens and Knowsley Hospitals NHS Trust	47	59	70	66	47
Stockport NHS Foundation Trust	26	50	73	57	33
Surrey and Sussex Healthcare NHS Trust	2				
Tameside Hospital NHS Foundation Trust	27	55	75	62	49
Taunton and Somerset NHS Trust	68	54	73	63	32
The Christie NHS Foundation Trust	19	63	83	69	39
The Hillingdon Hospital NHS Trust	21	57	69	63	45
The Mid Cheshire Hospitals NHS Trust	67	54	72	64	45
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	200	58	75	64	45
The Princess Alexandra Hospital NHS Trust	78	58	74	62	39
The Queen Elizabeth Hospital King's Lynn NHS Trust	77	62	76	71	52

#### Mean adjusted scores for organisations who participated in the PROMS study continued

Values are not derived for organisations for which there were fewer than 3 responses. Where this applied to all scores, the row is left blank.

(\*\*) is used when this applied to a single score

Organisational name	No. of 18 month questionnaires in analysis	Satisfaction with breast area appearance	Physical well being	Emotional well being	Sexual well being
The Rotherham NHS Foundation Trust	52	55	71	64	42
The Royal Marsden NHS Foundation Trust	15	61	75	68	60
The Royal Wolverhampton Hospitals NHS Trust	40	60	72	64	41
The Shrewsbury and Telford Hospital NHS Trust	94	55	74	63	41
The Whittington Hospital NHS Trust	11	51	68	63	68
United Lincolnshire Hospitals NHS Trust	36	66	70	68	44
University Hospital Birmingham NHS Foundation Trust	42	59	75	65	42
University Hospital of North Staffordshire NHS Trust	4	62	66	63	**
University Hospitals Bristol NHS Foundation Trust	48	59	71	65	47
University Hospitals Coventry and Warwickshire NHS Trust	85	58	70	65	45
University Hospitals of Leicester NHS Trust	165	59	72	65	46
University Hospitals of Morecambe Bay NHS Trust	45	58	81	67	46
Walsall Hospitals NHS Trust	23	69	77	74	53
West Hertfordshire Hospitals NHS Trust	48	52	73	65	44
West Middlesex University Hospital NHS Trust	16	51	75	69	44
West Suffolk Hospitals NHS Trust	49	55	73	61	37
Weston Area Health NHS Trust	29	57	74	65	53
Whipps Cross University Hospital NHS Trust	11	57	71	65	52
Winchester and Eastleigh Healthcare NHS Trust	45	55	76	62	43
Wirral University Teaching Hospital NHS Foundation Trust	7	50	76	57	32
Worcestershire Acute Hospitals NHS Trust	54	64	75	71	56
Worthing and Southlands Hospitals NHS Trust	90	60	75	67	43
Wrightington, Wigan and Leigh NHS Trust	2				
Yeovil District Hospital NHS Foundation Trust	35	59	72	67	44
York Hospitals NHS Foundation Trust	138	63	73	67	46

Organisational name	No. of 18 month questionnaires in analysis	Satisfaction with breast area appearance	Physical well being	Emotional well being	Sexual well being
BMI Bath Clinic	14	63	74	72	56
BMI Bishops Wood Hospital	2				
BMI Chelsfield Park Hospital	3	40	90	63	**
BMI Fawkham Manor Hospital	2				
BMI Mount Alvernia Hospital	22	58	74	68	46
BMI Priory Hospital	20	60	78	70	51
BMI Sarum Road Hospital	5	65	76	80	56
BMI The Beaumont Hospital	7	57	69	60	34
BMI The Blackheath Hospital	No questionnaires returned from consenting patients				
BMI The Cavell Hospital	1				
BMI The Chiltern Hospital	21	56	78	65	42
BMI The Droitwich Spa Hospital	4	69	75	71	**
BMI The Harbour Hospital	4	48	66	63	**
BMI The Highfield Hospital	No questionnaires returned from consenting patients				
BMI The Kings Oak Hospital	3	58	75	71	**
BMI The Manor Hospital	1				
BMI The Princess Margaret	21	57	78	66	43
BMI The Ridgeway Hospital	1				
BMI The Sandringham Hospital	4	49	77	48	**
BMI The Saxon Clinic	11	60	80	66	45
BMI The Shelburne Hospital	6	74	77	79	53
BMI The Sloane Hospital	8	72	72	78	46
BMI The Somerfield Hospital	14	56	71	63	51
BMI The Winterbourne Hospital	1				
BMI Thornbury Hospital	7	59	73	68	36
Cromwell Hospital	12	74	76	85	49
Hospital of St John & St Elizabeth	2				
Lister Hospital	No questionnaires returned from consenting patients				
Nuffield Health Bournemouth Hospital	No questionnaires returned from consenting patients				
Nuffield Health Brentwood Hospital	17	59	74	70	42
Nuffield Health Brighton Hospital	10	65	81	77	51
Nuffield Health Bristol Hospital	1				
Nuffield Health Cambridge Hospital	3	62	85	74	**
Nuffield Health Cheltenham Hospital	11	51	71	66	39
Nuffield Health Exeter Hospital	4	66	83	54	**
Nuffield Health Grosvenor Hospital	6	49	78	73	**
Nuffield Health Hereford Hospital	2				
Nuffield Health Ipswich Hospital	5	39	70	55	28
Nuffield Health Newcastle-upon-Tyne Hospital	1				
Nuffield Health North Staffordshire Hospital	2				
Nuffield Health Plymouth Hospital	2				
Nuffield Health Shrewsbury Hospital	1				
Nuffield Health Taunton Hospital	2				
Nuffield Health Tees Hospital	1				
Nuffield Health Tunbridge Wells Hospital	3	64	92	88	**
Nuffield Health Woking Hospital	4	62	80	77	41
Nuffield Health York Hospital	6	77	80	84	69
Parkside Hospital	7	68	73	61	47
Ramsay Euxton Hall Hospital	5	60	73	65	52
Ramsay Fitzwilliam Hospital	2				
Ramsay Oaks Hospital	No questionnaires returned from consenting patients				
Ramsay Rivers Hospital	5	64	80	70	**
Ramsay Springfield Hospital	8	59	74	59	**
Ramsay West Midlands Hospital	7	62	81	70	62
Spire Alexandra Hospital	2				
Spire Bristol Hospital	20	57	75	71	42
Spire Bushey Hospital	8	63	85	80	57
Spire Cambridge Lea Hospital	8	46	78	73	46
Spire Clare Park Hospital	No questionnaires returned from consenting patients				
Spire Elland Hospital	9	54	74	66	47
Spire Harpenden Hospital	2				



Organisational name	No. of 18 month questionnaires in analysis	Satisfaction with breast area appearance	Physical well being	Emotional well being	Sexual well being
Spire Hull and East Riding Hospital	No questionnaires returned from consenting patients				
Spire Leeds Hospital	14	61	79	64	46
Spire Little Aston Hospital	13	77	79	76	60
Spire Liverpool Hospital	1				
Spire Methley Park Hospital	1				
Spire Murrayfield Hospital Wirral	5	39	66	44	13
Spire Norwich Hospital	13	49	76	67	41
Spire Parkway Hospital	9	72	79	69	46
Spire South Bank Hospital	5	63	63	59	44
Spire Southampton Hospital	13	59	79	69	48
Spire Thames Valley Hospital	4	67	79	69	59
Spire Tunbridge Wells Hospital	1				
Spire Washington Hospital	1				
Spire Wellesley Hospital	1				
St Josephs Private Hospital	8	70	85	67	50
The Harley Street Clinic	No questionnaires returned from consenting patients				
The New Victoria Hospital	1				
The Princess Grace Hospital	36	64	79	74	48

#### Non-English NHS trusts

Organisational name	No. of 18 month questionnaires in analysis	Satisfaction with breast area appearance	Physical well being	Emotional well being	Sexual well being
Abertawe Bro Morgannwg University NHS Trust	4	56	80	63	**
Gwent Healthcare NHS Trust	87	57	73	64	40
Cardiff and Vale NHS Trust	22	53	67	58	37
Cwm Taf NHS Trust	13	54	72	72	50
NHS Grampian	No questionnaires returned from consenting patients				
North West Wales NHS Trust	75	61	75	67	53

## **95 per cent confidence intervals**

This interval indicates how certain we are that a value that we derive from a sample is close to the true value for the complete population. We would expect the 95 per cent confidence interval will not include the value for the population 5 per cent of the time. For example, if we took 100 random samples of women and measured their height, we would expect that the 95 per cent confidence interval for the average height in 95 samples would contain the value of the average height for the population of women.

## **ABS**

The Association of Breast Surgery (ABS) is the specialty society that represents breast cancer surgeons and is part of the British Association of Surgical Oncology. It is one of the key stakeholders leading the Audit.

## **Adjuvant treatment**

An additional therapy (eg chemotherapy, radiotherapy, hormone drug therapy) provided to improve the effectiveness of the primary treatment (eg breast cancer surgery). This may aim to reduce the chance of local recurrence of the cancer or to improve the patient's overall chance of survival. These treatments may be provided before or after surgery.

## **Autologous breast reconstruction**

The reconstruction of the breast mound (or shape) using only the patient's own tissue (without any prosthesis or implant).

## **Breast conserving surgery**

A surgical procedure to remove a discrete lump or abnormal area of tissue from the breast, without the removal of all breast tissue.

## **Breast reconstruction surgery**

The surgical recreation of the breast mound (or shape) after some or all of this has been lost or removed (eg after breast cancer surgery).

## **BAPRAS**

The British Association of Plastic, Reconstructive and Aesthetic Surgeons is the specialty society that represents plastic surgeons. It is one of the key stakeholders leading the Audit.

## **BASO**

The British Association of Surgical Oncology is a specialty society that is comprised of the Association of Breast Surgery and the Association of Cancer Surgery.

## **Cancer Registry**

The Cancer Registries (eight in England, and one each for Wales, Scotland and Northern Ireland) collect, analyse and report data on cancers in their area, and submit a standard dataset on these registrations to the Office for National Statistics.

## **CASU**

The Clinical Audit Support Audit is part of the NHS Information Centre for Health and Social Care, and manages a number of national clinical audits in the areas of cancer, diabetes and heart disease. It is one of the key stakeholders leading the Audit.

## **Chemotherapy**

Drug therapy used to treat cancer. It may be used alone, or in conjunction with other types of treatment (eg surgery or radiotherapy)

## **Comorbidity**

A coexisting medical condition that is unrelated to the primary breast cancer.

## **CRG**

The Audit's Clinical Reference Group is comprised of representatives of the key stakeholders in breast cancer care. They advise the Project Team on particular aspects of the project and provide input from the wider clinical and patient community.

## **CEU**

The Clinical Effectiveness Unit is an academic collaboration between The Royal College of Surgeons of England and the London School of Hygiene and Tropical Medicine, and undertakes national surgical audit and research. It is one of the key stakeholders leading the Audit.

## **Delayed breast reconstruction**

The reconstruction of the breast mound (or shape) after a mastectomy has already been performed. This is undertaken as a separate operative procedure.

## **Ductal carcinoma in situ (DCIS)**

A non-invasive/pre-invasive type of breast tumour that is confined to the lactiferous ducts.

## **Free flap breast reconstruction**

The breast mound (or shape) is reconstructed using the patient's own tissue (eg skin, fat, muscle) from another part of the body (donor area). The tissue is completely detached from the donor area before it is moved, with microsurgery used to rejoin its arteries and veins to those in the breast area. This means that tissue can also be taken from areas not adjacent to the breast, such as the buttock or thigh.

## **HQIP**

The Healthcare Quality Improvement Partnership was established in 2008. They aim to promote quality improvement in healthcare, and in particular increase the impact of clinical audit on the services provided by the NHS and independent healthcare organisations

## **HES**

Hospital Episode Statistics is a database which contains data on all inpatients treated within NHS Trusts in England. This includes details of admissions, diagnoses and those treatments undergone.

## ICD10

International Classification of Diseases, Tenth Revision. This is the World Health Organisation international standard diagnostic classification, and is used to code diagnoses and complications within the Hospital Episode Statistics database of the English NHS.

## Immediate breast reconstruction

The reconstruction of the breast mound (or shape) at the same time as the mastectomy, undertaken as part of the same operative procedure.

## The NHS Information Centre for health and social care

The NHS Information Centre is a special health authority that provides facts and figures to help the NHS and social services run effectively. The National Clinical Audit Support Programme (NCASP) is one of its key components.

## Implant-only breast reconstruction

The breast mound (or shape) is reconstructed using a tissue expander (the volume can be increased by injecting saline through a port placed under the skin) or a definitive implant (the volume is fixed). The expander or implant is placed under the pectoral (chest) muscle. A tissue expander may be exchanged for a definitive implant or left in place after expansion.

## Lymphoedema

Swelling due to the build up of protein-rich fluid in the tissues. In breast cancer patients this occurs when the lymphatic drainage system that normally removes this fluid is damaged by surgery or radiotherapy to the armpit. The swelling usually affects the arm on the treated side.

## Mastectomy

The removal of all breast tissue, usually performed as a treatment for breast cancer. Variations involve leaving some or all of the skin over the breast (skin-sparing) or removing some of the underlying pectoral muscle as well (total).

## Metastatic disease

When cancer has spread from the place in which it started to other parts of the body

## MDT

The breast cancer multi-disciplinary team is a group of professionals from diverse specialties that works to optimise diagnosis and treatment throughout the patient pathway.

## NICE

The National Institute of Health and Clinical Excellence is an independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

## ONS

The Office for National Statistics (ONS) is the government department responsible for collecting and publishing official statistics about the UK's society and economy. This includes cancer registration data.

## Pedicle flap breast reconstruction

The breast mound (or shape) is reconstructed by moving a 'flap' of skin, muscle and fat from the patient's back or abdomen to the breast area, while keeping intact a 'pedicle' or tube of tissue containing its supplying arteries and veins.

## Project Board

The Audit's Project Board consists of senior representatives of the key stakeholders and the Healthcare Quality Improvement Partnership, and acts to ensure that the Audit is meeting its contractual targets and objectives.

## Project Team

The Audit's Project Team consists of clinical, audit and management representatives of the key stakeholders and works on the design, implementation, analysis and reporting of the Audit.

## RCN

The Royal College of Nursing is an independent professional body that represents nurses and nursing, promotes excellence in practice and shapes health policies, and in particular aims to improve the quality of patient care.

## RCS

The Royal College of Surgeons of England is an independent professional body committed to enabling surgeons to achieve and maintain the highest standards of surgical practice and patient care. As part of this it supports Audit and the evaluation of clinical effectiveness for surgery.

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