National Mastectomy and Breast Reconstruction Audit

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

First Annual Report of the National Mastectomy and Breast Reconstruction Audit 2008

Prepared in association with:

[Logos of associated organizations]
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[Logos of the Royal College of Surgeons of England, BAPRAS, Royal College of Nursing, and Healthcare Commission]
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This is the first annual report from the National Mastectomy and Breast Reconstruction Audit. The report presents the first year’s work on the project including a pre-audit qualitative study, Hospital Episode Statistics (HES) analysis and organisational audit.

The National Mastectomy and Breast Reconstruction Audit collects information on all women (aged 16 and over) who undergo mastectomy and/or breast reconstruction between 1 January and 30 September 2008 in both the NHS and Independent sector. The results of the clinical data collection and patient reported outcomes study will be reported in subsequent reports starting in December 2008.

The aim of the audit is to describe provision of and access to breast reconstruction in England and Wales. Evaluate current clinical practice in mastectomy and breast reconstruction and measure outcomes following mastectomy with or without reconstruction and assess the quality of information provided to women undergoing mastectomy and their satisfaction with the reconstructive choices made.

The National Mastectomy and Breast Reconstruction Audit report is available to download from: http://www.ic.nhs.uk/mbr

Printed copies of this report can be ordered from The NHS Information Centre’s Contact Centre 0845 300 6016 or email: enquiries@ic.nhs.uk quoting document reference 18120107.

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1.0 Acknowledgements

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The Project Team would also like to acknowledge the support of Marialena Trivella, Clinical Effectiveness Unit, for carrying out the analysis of Hospital Episode Statistics data.

Finally, we would like to thank all stakeholders who participated in the qualitative study and all NHS Trusts and private hospitals who provided information for the organisational study.

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2.0 Foreword

I am writing this at the end of January 2008. We’re off! We’ve started the audit. My impression so far is that it is a bit like the start of the Grand National.

To continue the racing analogy, the race has got off to a rapid start with the appearance of a large number of horses in the first month. Thanks to all those who have registered so far.

The results in this annual report highlight the importance of carrying out a comparative clinical audit. Please remember that unlike many audits, where one completes a form and never know the result, this audit will allow hospitals to read their own inputted data. Hospitals will be able to compare their own results against a national average in real time through online reporting.

The ABS has a proud tradition of audit in breast cancer. The MBR audit is a unique, challenging and difficult audit which will benefit future generations of women with breast cancer. I urge you to give this your full support.

Once again, thank you for your enthusiastic participation - and the best of luck at Beecher’s!

Hugh Bishop
Association of Breast Surgery at
British Association of Surgical Oncology

I am delighted to be given this opportunity of writing in support of what must be considered to be one of the most ambitious projects yet carried out in the field of breast cancer reconstruction. The forward thinking of those surgeons from general and plastic surgery with an interest in breast surgery to form the Interface Breast Training Group of the Royal College of Surgeons of England was in itself revolutionary. The embarkation of this organisation on a four year national audit of the standard of care delivered nationally to women with breast cancer cannot be applauded highly enough. The results of the first year of this audit have revealed the real rather than the perceived situation as it stands today, identifying the significant problems being faced by breast surgeons in this era of ever decreasing ‘targets’ for the delivery of care. Bringing these facts to the surface and into the public arena must herald significant improvement in the management of this unfortunate group of patients. I very much look forward to reading the results of the next three reports, confident in the belief that this improvement will have been achieved and would like to proffer my appreciation and recognition of the enormous effort and dedication put in by those orchestrating this survey.

A. Roger Green FRCS
President
British Association of Plastic, Reconstructive and Aesthetic Surgeons
3.0 Executive Summary

The National Mastectomy and Breast Reconstruction Audit Project began on 1 January 2007. The key questions that the audit aims to answer are:

- is the provision of breast reconstruction services uniform across England and Wales?
- do women undergoing mastectomy have enough information to make an informed decision about breast reconstruction, and are they happy with that decision?
- what are the outcomes following mastectomy with or without breast reconstruction?

In 2002, the National Institute for Clinical Excellence (NICE) published the report ‘Improving Outcomes in Breast Cancer’\(^1\) that contained guidance on the organisation and delivery of services for people with breast cancer. Further guidance was published by the Association of Breast Surgery (ABS) at the British Association of Surgical Oncology (BASO) and the British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS).\(^2\) The key recommendations are that:

- all breast cancer patients should be managed by multi-disciplinary teams
- breast reconstruction should be available at the initial surgical operation
- breast cancer referrals should only be made to units which deal with at least 100 new cases per year
- there should be regular network-level audits of service provision and the outcomes attained, including an assessment of patients’ and carers’ experiences.

The National Mastectomy and Breast Reconstruction Audit is designed as a four year project. The focus of the audit will be a prospective examination of the determinants of variation in practice and outcomes for a cohort of women who will undergo mastectomy or reconstruction surgery during 2008. However, the audit also aims to provide a full picture of breast cancer services in England and Wales. To enable this, three additional pieces of work were performed in 2007 to investigate those aspects not easily addressed through prospective data collection at the individual patient level.

These comprised:

- a qualitative study of interviews with 30 stakeholders to highlight the characteristics of high quality surgical care for women with breast cancer and so inform the design of the clinical dataset and patient questionnaires to be used in the prospective audit
- an organisational survey of 144 NHS Trusts (93 per cent response rate) and 143 private hospitals (88 per cent response rate) to identify the characteristics of healthcare providers eligible for participation in the prospective audit
- a retrospective analysis of the Hospital Episode Statistics (HES) dataset to describe changes in the number of breast cancer operations performed in the English NHS between 1997 and 2006 and hence indicate the approximate number to be covered by the prospective audit.

The results of this additional work are presented in this first annual report. The main findings are summarised below.

**Overall quality of breast cancer surgery**

- Among the stakeholders who were interviewed for the qualitative study, there is a general perception that a good surgical service is available to women with breast cancer in England and Wales. There is a strong consensus among stakeholders about the determinants of high quality in breast cancer surgery. The following seven determinants were identified from the stakeholders’ responses:

  - service configuration
  - resources
  - communication with patients
  - time to allow informed and reasoned decision making
  - training of staff
  - communication between clinicians
  - defining and auditing quality standards and outcomes.
Service configuration

- There are considerable pressures upon service providers. These include the need to provide more operations because of the rising incidence of breast cancer and the requirement to provide a higher proportion of women with reconstructive options after mastectomy. Service providers in the English NHS responded to these pressures by increasing the number of operations performed from 24,684 to 33,814 over the period 1997 to 2006, a 37 per cent increase.

- The number of immediate reconstruction procedures provided by the English NHS almost doubled between 1997 and 2006. However, the proportion of all women undergoing mastectomy who received an immediate reconstruction increased only from 7 per cent to 11 per cent. This indicates that there have been difficulties in implementing guidance that immediate reconstruction should be made available to all women undergoing mastectomy.

- Local access to breast reconstruction services is not uniform across England and Wales. Although falling in number, 39 English NHS Trusts (26 per cent) that performed mastectomy surgery in 2005-06 did not also provide immediate reconstruction as a local option according to HES.

- There is considerable variation between and within the NHS and private sectors with respect to the use of chemotherapy before surgery to enable the offer of an immediate reconstruction. 55 per cent of NHS Trusts would provide the option of such therapy to a woman with metastatic disease while 45 per cent would not. 72 per cent of private hospitals said they would provide this option to women with metastatic disease. The variation observed is likely to create inequities in access to immediate breast reconstruction.

Resources

- There is a perception that the current funding climate within the NHS creates disincentives to increase access to breast reconstruction. Some service commissioners may create barriers to the availability of breast reconstruction by, for example, insisting upon a psychological evaluation. Some service providers have responded to resource shortages by ring fencing hospital beds for breast cancer patients.

Communication with patients

- Breast care nurses have a key role in supporting patients through the decision about whether or not to have a breast reconstruction at the same time as their mastectomy. Seven NHS Trust employ only one such nurse. This means patients may be unable to access specialist nursing care if the sole nurse is away on annual or sick leave. 11 per cent of private hospitals providing breast cancer surgery report that they do not directly employ a breast care nurse. The 2002 NICE report, states that a specialist breast care nurse should be available to all patients with breast cancer, and involved as a core member of any breast cancer multi-disciplinary team.

Time to allow informed and reasoned decision making

- The decision to proceed with immediate breast reconstruction is difficult and women require adequate time to digest the information and choices available. There is a perception that decisions about reconstruction are often relegated to a secondary concern because of the urgent need to move the patient to definitive treatment within the 62 day window laid down by the 2000 NHS Cancer Plan.
Training of staff

- In 2005-2006, one third of all the English NHS Trusts that performed breast reconstruction surgery for women performed less than six such procedures, indicating that reconstruction surgery is still performed at Trusts with relatively little experience in the field. These centres provide a poor environment for surgeons to train and improve their breast reconstruction skills. The recent ABS and BAPRAS guidance recommends that a caseload of at least 25 major reconstructive procedures per annum is required for a Trust to be recognised as an oncoplastic training unit.

- One encouraging development is the breakdown in surgical specialty boundaries as evidenced, for example, by the 80 NHS Trusts who report that general surgeons with a specialty interest in breast surgery now perform pedicle flap breast reconstructions. The innovative oncoplastic breast training programme established by BAPRAS and the ABS may have stimulated this development.

Communication between clinicians

- A fifth of the NHS Trusts that perform breast cancer surgery do not have a consultant oncologist, pathologist or radiologist with a specialist interest in breast cancer within the Trust. This may impair the quality of diagnostic services and adjuvant (non-surgical) therapy planning for women treated at these centres. The 2002 NICE report, states that these consultants are core members of the multi-disciplinary team and are essential to providing appropriate diagnostic and therapeutic services.

- 94 per cent of private hospitals report that the needs of their breast cancer surgery patients are discussed at a multi-disciplinary team elsewhere. This may impair the quality and speed of decision making about breast reconstruction for these patients and inhibit local efforts to audit the quality of care although quantitative evidence to support this claim is not yet available.

- The prospective audit will allow for a more detailed investigation of the relationship between multi-disciplinary team structures and the quality of care provided.

Defining and auditing quality standards and outcomes

- 90 per cent of NHS Trusts and 61 per cent of private hospitals contribute to one or more national clinical datasets on breast cancer care. However, most of these datasets contain only limited information on surgical practices and outcomes. This makes it difficult to understand the reasons why some women do or do not proceed to breast reconstruction after mastectomy. The National Mastectomy and Breast Reconstruction Audit has been designed to remedy this information deficit and it is hoped that all NHS and private centres carrying out breast cancer surgery in England and Wales will participate.
4.0 Background

4.1 Breast cancer treatment
Breast cancer is the most common form of female cancer, accounting for nearly 30 per cent of all cases of cancer in women. There were 39,301 new cases of breast cancer amongst women in England and Wales in 2004, an increase of 27 per cent over 10 years. 10,969 women died from the disease in 2005 (Office for National Statistics). Breast cancer can also occur in men but this form of the disease is not discussed hereafter.

Women with breast symptoms are usually referred by their GP to a breast specialist for a triple assessment. Triple assessment involves a clinical examination of the breast; a form of breast imaging – usually ultrasound in young women and mammography in older women; and a cell or tissue sample being taken from the abnormal area. The results of this triple assessment will decide the diagnosis and any further treatments that may be provided. A second route into the treatment pathway is via the NHS Breast Screening Programme. All women between 50 and 70 are invited to undergo regular screening, the intention being to pick up cancers that are not palpable (capable of being felt). The screening assessment may be performed at a hospital or mobile unit, and involves mammography of the breast. The images are then reviewed and reported on by a specialist who decides if there are any suspicious findings. If these are present, the woman is referred to a breast specialist in a screening programme clinic to undergo a full triple assessment and proceed to treatment as necessary.

Surgery continues to be the first line treatment for breast cancer for many women. The treatment of early breast cancer may involve removal of part of the breast tissue (breast conserving surgery) or all breast tissue (mastectomy). In either case, surgery may also be required to restore the cosmetic appearance following loss of breast tissue.

4.2 Development of breast cancer surgery
The goal of breast cancer treatment has shifted from a traditional emphasis on tumour ablation to therapy designed to restore the patient to wholeness, providing the maximum possible quality of life while controlling malignancy. Through collaboration between plastic and breast surgeons there have been significant enhancements in service delivery to patients with breast cancer. The Breast Oncoplastic Service is defined as a core component of the breast multi-disciplinary team with sufficient experience to offer patients access to the full range of procedures encompassed by oncoplastic breast reconstructive surgery, which include:

- appropriate adequate surgery to extirpate the cancer
- partial reconstruction to correct wide excision defects
- immediate and delayed total reconstruction with access to a full range of techniques
- correction of asymmetry of the reconstructed and the contralateral unaffected breast.

4.2.1 Mastectomy
Mastectomy is recommended when the breast would be significantly distorted by the removal of a large cancer, when the tumour is directly behind the nipple, when the cancer is multi-focal (in more than one area of the breast), or where there are widespread lesions within the breast. The type of mastectomy depends on many factors such as size of tumour, location and tumour type and whether the patient intends to undergo reconstructive surgery. Some women may also have a preference for mastectomy rather than breast conserving surgery.

4.2.2 Breast reconstruction
Breast reconstruction is an operation to create a breast shape to match the remaining breast and regain symmetry following mastectomy. This can be done either at the same time as the initial mastectomy or at a later stage. The decision for immediate reconstruction versus delayed reconstruction will depend on a number of clinical issues (adjuvant treatment plans) as well as patient choice. In line with guidance issued by NICE in 2002, breast reconstruction should be discussed with all patients who require mastectomy.

There are several different techniques used to reconstruct a breast, these include:

- implant-only reconstruction
- ‘autologous’ reconstruction using the patient’s own tissue
- a combination of both these methods.
Tissue reconstruction most commonly involves 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. ‘Free flap’ reconstruction involves the tissue being 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 technique means that tissue can also be taken from areas not adjacent to the breast, such as the buttock or thigh.

4.3 Background to the audit

Rising public awareness, heightened trainee expectations and growing collaboration between breast and plastic surgeons were the catalyst that triggered the formation of an Interface Breast Training Group at the Royal College of Surgeons of England in 2000. This group was established to improve the availability and outcomes of breast reconstruction for patients through better education and training, both for breast and for plastic surgeons at all levels of experience. The Interface Group was supported by BAPRAS and by the ABS, and their subcommittees.

The early developmental work carried out by this group led to two new initiatives that have propelled the debate about breast reconstruction onto the national stage. The original proposal for a national audit was submitted to the Commission for Healthcare Audit and Inspection in 2003, and was resubmitted to the Healthcare Commission in 2005. An amended audit proposal was submitted successfully to the Commission the following year. The National Mastectomy and Breast Reconstruction Audit is the first of its kind in the world, and will include all women in England and Wales undergoing mastectomy as well as all those undergoing immediate and delayed breast reconstruction.
5.0 Details of audit/Introduction

Breast reconstruction following mastectomy for breast cancer is an evolving area of care in England and Wales. Different techniques for reconstruction have been introduced in recent years, and as a result there is considerable variation in the practices of different healthcare providers. There is also variation in the larger issue of patient indications for reconstruction, with uncertainty about the safety of immediate reconstruction in certain patients. As a result there is the potential for geographical inequities in care, with the likelihood of being offered breast reconstruction often depending on the hospital at which a patient is treated.

5.1 Key questions

The key questions to be addressed in the audit are:

• is the provision of breast reconstruction services uniform across England and Wales?

• do women undergoing mastectomy have enough information to make an informed decision about breast reconstruction, and are they happy with that decision?

• what are the outcomes following mastectomy with or without breast reconstruction?

To address the key questions listed above the audit has six objectives.

• To quantify the current volume of reconstruction surgery performed in England and Wales at both NHS and private centres.

• To explain reasons for variation in access to and uptake of reconstruction, such as patient characteristics (e.g. co-morbidities), and healthcare provider processes (e.g. type of information and advice given to patients).

• To describe current clinical practices in breast cancer surgery, and to explain variation in practice using data on patient characteristics and healthcare provider identity.

• To describe outcomes following mastectomy with or without reconstruction. Both patient reported outcomes (e.g. satisfaction and quality of life), and clinical outcomes (e.g. peri operative complications, local cancer recurrence and survival) will be collected (within the timetable of the audit).

• To explain variation in outcomes using data on patient characteristics, tumour characteristics, clinical practices and identity of healthcare provider.

• To address nationally agreed standards. As evidence based standards are unavailable at present the focus of the audit will be on producing standards rather than auditing against such standards.

5.2 The design of the audit

The focus of the audit will be a prospective audit of a cohort of women undergoing breast cancer surgery that includes the collection of clinical and patient reported outcomes data. Women who undergo mastectomy and breast reconstruction surgery during the first nine months of 2008 will be included.

In addition, the audit includes three additional pieces of work which were performed in 2007. These investigated aspects of service provision that are not easily addressed with prospective data collection on the treatment of individual women and their outcomes. The three pieces of work were:

• a qualitative study of interviews with 30 stakeholders to highlight the characteristics of high quality surgical care for women with breast cancer and so inform the dataset and patient questionnaires to be used in the prospective audit

• an organisational survey of 144 NHS Trusts and 143 private hospitals carried out to identify the characteristics of healthcare providers eligible for participation in the prospective audit

• a retrospective analysis of the HES dataset to describe changes in the number of breast cancer operations performed in the English NHS between 1997 and 2006 and indicate the approximate number of operations that will be covered by the prospective audit.

In 2007, there has been considerable effort to prepare for the prospective audit component of the project, including design of a clinical dataset and patient questionnaires, a pilot project and recruitment of NHS and private hospitals. To facilitate the latter task, five ‘roadshows’ took place around the country. Prospective data collection began on 1 January 2008 and will run till 30
September 2008. To date more than 100 NHS trusts and 50 private hospitals have registered to take part in the prospective study. Private hospital participation has been actively encouraged by those who accredit such units for breast cancer surgery and insurers such as BUPA.

5.3 Annual reports

This project will take four years to complete. Planning and feasibility work began on 1 January 2007. In this first annual report the results of the qualitative study, organisational survey and retrospective analysis of HES are presented.

The second annual report (December 2008) will provide a more complete analysis of existing datasets. In addition to an analysis of existing data held by the Patient Episode Database Wales (PEDW), it will report on an attempt to combine HES and Cancer Registry data available for the last nine years. It will also provide an analysis of clinical data collected in the prospective audit. For example:

- description of patients’ demographic and clinical characteristics
- description of clinical practices
- explaining variation in patient characteristics and clinical practices
- describing peri-operative outcomes e.g. complications
- explaining variation in peri-operative outcomes.

The third annual report (December 2009) will answer all questions that can be covered by analysis of questionnaires completed by patients three months after surgery. For example:

- appropriateness of information and advice provided about breast reconstruction
- reconstructive choice offered and planned in future
- post-discharge complications and intervention
- the relationship between clinical risk factors identified during the peri-operative period and the patient’s care experience.

The fourth annual report (December 2010) will answer all questions that can be covered by analysis of eighteen month patient reported outcome questionnaires. For example:

- levels of patient quality of life, function and satisfaction
- the relationship between clinical risk factors identified during the peri-operative period and the eighteen-month patient reported outcomes.

5.4 The project team

This audit is a collaboration between the Association of Breast Surgeons at the British Association of Surgical Oncology, the British Association of Plastic Reconstructive and Aesthetic Surgeons and the Royal College of Nursing, supported by the Clinical Effectiveness Unit at the Royal College of Surgeons of England and the National Clinical Audit Support Programme (NCASP) at The NHS Information Centre for health and social care. All of these organisations have a long standing interest in the audit of breast cancer surgery and are delighted that the Healthcare Commission has decided to prioritise and fund this national clinical audit of mastectomy and breast reconstruction.
6.0 The challenges of delivering high quality breast care surgery service: a qualitative study

As the first step in this audit, a qualitative study was carried out to identify the most serious deficiencies in the quality of current care. This study aimed to identify opportunities to improve the quality of breast cancer surgery from the perspective of patients, clinicians and others involved in commissioning and providing the service. It was also hoped that the study would involve stakeholders from the outset to encourage “ownership” of the audit.

The specific objectives were:

• to define what constituted high quality care for patients undergoing breast cancer surgery
• to identify current problems in effectively delivering this care
• to inform the design of the clinical dataset and patient questionnaires to be used in the prospective audit.

Over a three-month period in 2007, thirty stakeholders with experience and knowledge of the care delivered to patients with breast cancer were interviewed. The sample comprised:

• five patients
• two patient representatives from the voluntary sector
• one breast surgeon not performing reconstruction
• four breast surgeons performing reconstruction
• four plastic surgeons
• two breast care nurses
• one anaesthetist
• one radiologist
• one oncologist
• one physiotherapist
• two private healthcare representatives
• one Cancer Registry lead
• one Cancer Network lead
• one Welsh Assembly representative
• two Department of Health representatives involved in cancer policy formulation
• one audit lead at the Healthcare Commission.

Seventeen interviewees were members of the audit’s Clinical Reference Group (CRG) and the remaining 13 were nominated by the CRG’s members to cover areas in which additional information was deemed necessary. A semi-structured interview format was used to identify the key determinants of quality in breast cancer surgery.

The following sections summarise the results of these interviews. Qualitative methods are an accepted means for addressing complex aspects of healthcare provision and identifying conceptual themes.

Definition of high quality care for patients undergoing breast cancer surgery

Overall, many interviewees, patients as well as healthcare professionals, indicated that “generally speaking it all works very well.” Surgeons said that they felt that they were able to deliver a reconstruction to everybody who wants it and that over a period of time “an environment (was created) where everything works.”

An analysis of the interviews highlighted seven characteristics of high quality care:

• service configuration
• resources
• communication with patients
• time to allow informed and reasoned decision making
• training of staff
• communication between clinicians
• defining and auditing quality standards and outcomes.

Each of these themes will now be briefly discussed along with any problems in delivering them.
Service configuration

High quality care was defined by one interviewee as the provision of “the most appropriate treatment at the most appropriate time by the most appropriate person.” To ensure this, interviewees said that it is essential to have in place a service that uses resources efficiently while providing timely access to diagnosis and treatment for all. A number of options to achieve this were mentioned:

- standardised referral pathways with a single point of entry
- clear communication between GP and breast unit
- access to same breast cancer surgery services regardless of geographical location
- identification of inappropriate referrals

A number of barriers to realising these options were mentioned:

- Lack of management support; the uptake of breast reconstruction is not covered by an explicit national target.
- Impact of current national cancer waiting times targets; these targets aim to ensure the definitive treatment of all symptomatic breast cancer patients within 62 days from initial referral; in an attempt to meet these targets, surgeons may discourage patients who wish to opt for immediate breast reconstruction at the time of their mastectomy.
- “Haphazard” follow-up arrangements; as a result, patients may lose contact with their surgeon and breast cancer nurse when they are referred to the oncology team; problems may also arise for patients when they need to access specialist services for wound, lymphoedema and prosthesis problems during adjuvant therapy.

Resources

Interviewees mentioned three aspects of the services that are strongly dependent on the available resources.

- Facilities; interviewees highlighted the importance of a patient friendly out-patient clinical environment that ensures patients’ dignity and privacy as well as the availability of theatre and bed capacity to provide a full reconstructive service.
- Staffing; the need to have a team that includes all specialties involved in breast cancer care (radiologists, pathologists, oncologists, breast care nurses, breast surgeons, reconstructive surgeons, physiotherapists); after discharge, easy access to wound, prosthesis, lymphoedema and counselling services was seen as essential.
- Availability of reconstruction; interviewees indicated that “a full repertoire of reconstruction” should be available to all patients.

It was felt that “not enough money” is made available for breast reconstruction and that many providers “just wouldn’t have the resources” to offer all women a breast reconstruction. Most clinicians who felt they did not have major problems with their current rate of reconstruction indicated that they would struggle to meet an increased demand. It was also indicated that the current funding climate made it unlikely that Trusts would opt to do “lots of complicated surgery which takes more time, is more expensive and will not help to meet the targets.”

Interviewees said that reductions in staff as well as problems with recruiting experienced staff can make it difficult to build up a complete multi-disciplinary team (MDT). As a result, some specialists are not always available locally. This may impact on the treatment that is available to women. For example, some MDTs do not include a surgeon with knowledge of the reconstructive options available and as a result those MDTs might more often recommend breast conserving surgery, particularly in women with relatively large or high grade tumours.

It was claimed that commissioners introduce barriers to the availability of reconstruction. For example, some Primary Care Trusts fund reconstruction but refuse to fund surgery to the other breast required to obtain symmetry. Other Primary Care Trusts require a formal psychological assessment before breast reconstruction, a standard that some hospitals find difficulty in meeting.
Communication with patients

The interviewees felt that providing patients with appropriate and sufficiently detailed information about breast cancer surgery is essential to high quality care. This involves access to complete information about the diagnosis, management options, prognosis and outcomes.

Interviewees said that it is also important:

- to create an environment in which patients feel that “they can raise emotional problems and concerns without feeling silly or downtrodden”
- to make sure that family and care givers are included in the discussion about the treatment options
- to make photographs available of the outcomes that are obtained with the different treatments
- to offer women the chance to talk to others who have undergone the surgery
- to inform patients about peer and charity support groups that can offer emotional and psychological support.

The patients who were interviewed mentioned a number of problems.

- The poor quality of the provided information; one patient said that she “could find better information [on the internet] than from the actual service.”
- Not enough information was provided early in the treatment when it can help patients to make choices about their treatment.
- Breast reconstruction is sometimes offered in a discouraging way. This was described as “manipulation of vulnerable patients at the time of their cancer diagnosis” by one of the interviewed surgeons.

Time to allow informed and reasoned decision making

Many interviewees felt that informed choices about breast reconstruction are not possible without time for patients to obtain, digest and discuss information relevant to their care and decision making. While timely care is important, patients need time to ask questions and avoid making complex decisions without sufficient information.

It was felt by some interviewees that best care “isn’t necessarily best served by single consultations” and patients should be allowed to discuss their treatment “at the first, the second and the third consultation.” This would ensure that a patient’s treatment choice is “not just a knee jerk reaction but something they can live with at the end.”

Interviewees felt that he national target requiring all women referred with symptoms of breast cancer to receive definitive treatment within 62 days of initial referral is the main barrier to allowing patients sufficient time to make a decision about their treatment. They said that it was often difficult to schedule out-patient appointments to allow a patient to have a full discussion regarding her treatment options with a surgeon or breast care nurse. It was suggested that this may be one of the most significant factors preventing the uptake of immediate breast reconstruction by women in England and Wales.

Training of staff

Many interviewees mentioned the importance of:

- the quality of the training of the surgeons who provide breast reconstruction
- the training for breast cancer nurses given their role as patient advocates and “reconstructive gatekeepers.”

The surgical interviewees said that “improving training of (reconstructive surgeons) and the quality of those entering the specialty” are essential in ensuring the quality of breast cancer surgery. They also said that surgeons performing breast reconstruction surgery should be properly trained and accredited.

Surgical interviewees claimed that many breast surgeons rely on their plastic surgery colleagues for the provision of reconstructive expertise. Although this “two team” approach was thought to work extremely well in many cases, this lack of training and expertise on the breast surgeon’s part could make them more likely to “not want to refer patients who they can’t perform surgery on themselves.”
A breast surgeon felt that these problems were a direct result of training issues and that “a huge amount has to be done in training (breast) oncoplastic surgeons in aesthetic breast techniques.” As a consequence, “too few plastic surgeons are too stretched doing too much, as I think plastic surgery specialists don’t like to go down the breast route.” Problems with training reconstructive surgeons were said to have led to a workforce that is not completely skilled in reconstruction post-mastectomy.

Finally, interviewees reported their perception of huge differences in terms of the training, activity, and accessibility of breast care nurses. It was claimed that these differences lead to significant variations in the quality of care and support provided to women with breast cancer.

**Communication between clinicians**

All clinical interviewees felt that the presence of an effective MDT helps to ensure high quality patient care. They felt that it is vital to ensure access to the “skills and quality of the multi-disciplinary team – diagnostic, decision making, cohesion, operative and communication.”

Patients reported their concerns with the communication between clinicians of different disciplines. This was thought to have a negative effect particularly on referrals from primary care to breast units. In addition, concerns with referrals from surgical to oncology departments were mentioned as well as with those made to other providers if treatments were not available locally.

A number of clinicians pointed explicitly towards problems in communication between surgeons. They identified problems such as a reluctance to refer out of the unit, antipathy between teams, breast surgeons not wanting to refer patients that they can not perform surgery on themselves, and problems with communication between breast and plastic surgeons.

**Defining and auditing quality standards and outcomes**

Interviewees highlighted the importance of identifying key standards of practice and care, and then auditing current practice against these standards.

It was felt that all NHS Trust and private hospitals should be “explicit in the information (provided) and able to produce figures of outcomes.” Identifying key outcome measures following mastectomy and breast reconstruction surgery was seen as the only way to measure the efficacy and quality of care provided. Without knowing the outcomes of successful treatment and rehabilitation, it is not possible to measure the quality of care or provide a benchmark for the future.

Interviewees identified two main problems in auditing breast cancer surgery practices and outcomes:

- a lack of high quality evidence; as a consequence, it is impossible to develop meaningful national standards of process or outcomes
- the difficulty in identifying measures that truly reflect the quality of care provided.
A survey was undertaken to identify the location and characteristics of the organisations involved in providing breast cancer surgery. The objectives of the survey were:

- to identify centres carrying out mastectomy and breast reconstruction surgery
- to specify multi-disciplinary team composition, number of breast care nurses, and bed capacity at each centre
- to establish the types of mastectomy, breast reconstruction procedures, and chemotherapy carried out at each centre.

The information gathered will be used:

- to identify the population of centres carrying out various forms of breast cancer surgery in England and Wales
- to provide data on centre level characteristics that may be used to explain variation in patient level outcomes.

A list of all organisations (NHS Trusts and private hospitals) involved in breast cancer surgery was prepared from a wide range of sources. All NHS Trusts and private hospitals not on this list were contacted to make sure that no provider was missed. Questionnaires were posted to named contacts at every Trust/private hospital thought to be performing mastectomy or breast reconstruction surgery in England and Wales in 2007. These contacts included all breast cancer lead clinicians at NHS Trusts and, for the 42 NHS Trusts which contain a plastic surgery unit, the plastic surgery clinical directors. The primary contact in the private sector was the hospital chief executive. Reminders (written, e-mail and by telephone) continued (to a secondary contact if necessary) until an acceptable response rate was obtained.

Of the 155 NHS breast cancer lead clinicians contacted, 140 (90 per cent) returned completed questionnaires, as did all 42 (100 per cent) of the NHS plastic surgery clinical directors. As a result, completed questionnaires responses were obtained from 144 (93 per cent) NHS Trusts providing mastectomy or breast reconstruction. Of the 163 chief executives of private hospitals who were contacted, 143 (88 per cent) returned a completed questionnaire.

Of the 144 Trusts that returned a questionnaire, 102 (71 per cent) do not house a plastic surgery unit, 40 (28 per cent) contain a plastic surgery unit working alongside general surgeons with a sub-specialty interest in breast surgery, and two (one per cent) were Trusts where breast cancer surgery is performed exclusively by plastic surgeons.

The results of the organisational survey are shown in Figure 1. Some respondents did not complete all items on the questionnaire. The levels of missing data are shown in the figure, and where proportions are given in the text below, missing data has been excluded.

**Reserved beds for breast cancer surgery patients**

Only 50 (35 per cent) of the NHS Trusts surveyed reported that they have reserved beds for breast cancer surgery patients. Of the 102 NHS Trusts without a plastic surgery unit, 29 (29 per cent) have reserved breast cancer/breast reconstruction beds. This compares with 21 (52 per cent) of the 40 Trusts with both breast and plastics units, and neither of the two Trusts with isolated plastic surgery units. Only four (3 per cent) of the 143 private hospitals have reserved beds for breast cancer surgical patients.

**Consultants with a specialist interest in breast cancer diagnosis and treatment**

Figure 1 demonstrates that almost all NHS Trusts or private hospitals employ a consultant breast surgeon. However, a consultant plastic surgeon with an interest in breast cancer treatment is employed only by about half of the NHS Trusts and about three quarters of the private hospitals. Figure 1 also demonstrates that a number of NHS Trusts do not have a consultant oncologist, pathologist or radiologist with a specialist interest in breast cancer employed within the Trust. The absence of these specialists in private hospitals is higher.
Figure 1: Results of organisational survey of NHS Trusts and private hospitals in England and Wales that perform breast cancer surgery.

<table>
<thead>
<tr>
<th>Question</th>
<th>NHS Trusts (N = 144)</th>
<th>Private Hospitals (N = 143)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reserved beds for breast cancer surgery?</td>
<td>50 (35.5) 3</td>
<td>4 (2.9) 5</td>
</tr>
<tr>
<td>Consultants with a specialist interest in breast cancer?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Breast surgeon</td>
<td>142 (99.3) 1</td>
<td>141 (98.6) 0</td>
</tr>
<tr>
<td>• Plastic surgeon</td>
<td>79 (56.0) 3</td>
<td>106 (74.1) 0</td>
</tr>
<tr>
<td>• Oncologist</td>
<td>121 (87.7) 6</td>
<td>109 (76.2) 0</td>
</tr>
<tr>
<td>• Pathologist</td>
<td>126 (92.0) 7</td>
<td>79 (55.2) 0</td>
</tr>
<tr>
<td>• Radiologist</td>
<td>126 (91.3) 6</td>
<td>111 (77.6) 0</td>
</tr>
<tr>
<td>Dedicated breast care nurses?</td>
<td>136 (96.5) 3</td>
<td>125 (88.7) 2</td>
</tr>
<tr>
<td>Private hospitals patients discussed at outside MDT?</td>
<td>-</td>
<td>135 (95.1)</td>
</tr>
<tr>
<td>Pedicle flap reconstruction by breast surgeons?</td>
<td>80 (56.3) 2</td>
<td>69 (48.6) 1</td>
</tr>
<tr>
<td>Free flap reconstruction by breast surgeons?</td>
<td>2 (1.4) 1</td>
<td>15 (10.6) 1</td>
</tr>
<tr>
<td>Mastectomy procedures by plastic surgeons?</td>
<td>12 (8.5) 3</td>
<td>11 (7.7) 0</td>
</tr>
<tr>
<td>Carry out immediate reconstructions?</td>
<td>119 (84.4) 3</td>
<td>113 (83.1) 7</td>
</tr>
<tr>
<td>Carry out delayed reconstructions?</td>
<td>116 (83.5) 5</td>
<td>120 (93.0) 14</td>
</tr>
<tr>
<td>Mastectomies done for patients from other Trusts?</td>
<td>48 (34.0) 3</td>
<td>-</td>
</tr>
<tr>
<td>Reconstructions done for patients from other Trusts?</td>
<td>50 (36.2) 6</td>
<td>-</td>
</tr>
<tr>
<td>Chemotherapy use before surgery to enable immediate reconstruction?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• High grade</td>
<td>97 (74.0) 13</td>
<td>108 (82.4) 12</td>
</tr>
<tr>
<td>• Locally advanced</td>
<td>102 (77.9) 13</td>
<td>107 (82.3) 13</td>
</tr>
<tr>
<td>• Metastatic</td>
<td>68 (55.3) 21</td>
<td>92 (72.4) 16</td>
</tr>
<tr>
<td>Compliance with NICE guidance?</td>
<td>128 (92.1) 5</td>
<td>118 (82.5) 0</td>
</tr>
<tr>
<td>Contribution to national datasets?</td>
<td>124 (89.9) 6</td>
<td>82 (60.7) 8</td>
</tr>
</tbody>
</table>
Dedicated breast care nurses

Breast care nurses play a central role in providing information to breast cancer surgery patients and supporting them during the decision making process. 136 (97 per cent) NHS Trusts and 125 (89 per cent) private hospitals reported that they have a dedicated breast care nurse. When present, NHS Trusts employ an average of three breast care nurses and private hospitals an average of 1.5 nurses. Seven (five per cent) NHS Trusts and 60 (43 per cent) private hospitals reported that they employ only one breast care nurse.

MDT access in the private sector

135 (95 per cent) private hospitals reported that the needs of their breast cancer surgery patients are discussed at an MDT elsewhere.

Types of mastectomy and breast reconstruction surgery performed

There is evidence that traditional surgical specialty boundaries are breaking down, particularly within the private sector. It is now relatively common for general surgeons with a specialist interest in breast surgery to perform pedicle flap procedures, with 80 (56 per cent) NHS Trusts and 69 (49 per cent) private hospitals reporting such practices. At two (one per cent) NHS Trusts and 15 (11 per cent) private hospitals free-flap reconstruction procedures are performed by breast surgeons while at 12 (eight per cent) NHS Trusts and 11 (eight per cent) private hospitals mastectomies are performed by plastic surgeons.

Immediate and delayed breast reconstruction

119 NHS Trusts (84 per cent) reported that they perform immediate reconstruction and 116 (83 per cent) said they perform delayed reconstruction. All 42 Trusts with a plastic surgery unit carry out both immediate and delayed breast reconstruction. Of the 102 NHS Trusts without plastic surgery units, 78 (79 per cent) perform immediate reconstruction and 75 (77 per cent) perform delayed reconstruction. 113 (83 per cent) of the private hospitals reported that they perform immediate reconstruction and 120 (93 per cent) perform delayed reconstruction. Eighteen (13 per cent) of the Trusts and seven (five per cent) of the private hospitals that perform mastectomies reported that they perform no breast reconstruction surgery.

Provision of mastectomy and reconstruction surgery for other Trusts

Patients are sometimes referred to other NHS Trusts for mastectomy and/or breast reconstruction. The survey indicated that mastectomy operations are provided for other Trusts’ patients by 48 (34 per cent) of all NHS Trusts. Breast reconstruction is similarly provided for others by 50 (36 per cent) Trusts. Of the 42 NHS Trusts with a plastic surgery unit, 40 (95 per cent) provide reconstruction for patients referred from other NHS Trusts. This information was not collected from private hospitals as they are not involved in official NHS referral pathways for mastectomy and breast reconstruction.

The use of chemotherapy before surgery and its effect on offers of immediate reconstruction

Chemotherapy before surgery is increasingly being used to achieve loco-regional control in women with high grade (aggressive) tumours, locally advanced or metastatic disease. This treatment aims to reduce the size and spread of the cancer and the extent of surgery required. After recovery, mastectomy and immediate reconstruction may then be carried out.

Three quarters of NHS Trusts reported that they would provide such chemotherapy to patients with high grade or locally advanced disease to enable the offer of immediate reconstruction, but only half of the Trusts would do so in the case of metastatic disease. Private centres appeared more willing to provide such chemotherapy to all three groups.

Compliance with NICE guidance

NICE in their 2002 ‘Improving Outcomes in Breast Cancer’ report made one key recommendation of relevance to breast reconstruction surgery.

“Reconstruction should be available at the initial surgical operation. If this cannot be provided within one month of diagnosis, women should be offered a choice between routine surgery with delayed reconstruction (if desired), or waiting longer for initial surgery.”

In total, 128 (92 per cent) NHS Trusts and 118 (83 per cent) private hospitals stated that they comply with the recommendation.
Contribution to national clinical datasets

Ninety per cent of NHS Trusts and 82 per cent of private hospitals report that they contribute to one or more national clinical datasets for breast cancer. The most commonly named were the NHS Breast Screening Programme/Association of Breast Surgeons dataset and the Breast Cancer Clinical Outcome Measures dataset.
Breast reconstruction is a rapidly evolving field, with an increasing number of surgeons and Trusts perceived to be offering such procedures. It is unclear as to how these changes have affected women’s access to immediate or delayed reconstruction. The objective of this work is to identify trends in the number and type of operations performed on women with breast cancer and the number of Trusts and private hospitals at which they are provided.

This data will provide data on the impact of recent national guidance on:
- access to immediate reconstruction
- centre level volumes of breast reconstruction surgery.

Analyses were performed using the HES database of the Department of Health in England. This database records medical, demographic and administrative data relating to all patients admitted to National Health Service hospitals in England. It includes private patient admissions to NHS hospitals but not patients treated within private hospitals.

Data were extracted from the HES database for 1997-1998 to 2005-2006 for all female patients with an International Classification of Diseases (tenth revision) diagnostic code for malignant neoplasm of the breast (breast cancer). This data was then analysed using STATA 9.2 and Microsoft Excel statistical analysis software to describe trends in breast conserving, mastectomy, and immediate and delayed reconstruction surgery. This included changes in the number of Trusts performing this type of surgery and the number of cases performed at each Trust. The operations identified in this analysis include procedures performed for recurrent breast cancer and breast cancer secondary to another cancer as well as for primary breast cancer.

### Number and relative proportion of different types of breast cancer surgery

Figure 2 shows the number and relative proportion of breast cancer surgery procedures carried out for women in the NHS in England between 1997 and 2006. The number of breast conserving operations (e.g. lumpectomy) performed annually increased from 14,090 to 19,962. Over the same period, the

---

**Figure 2:** Hospital Episode Statistics information on trends in breast cancer surgery for women in England, 1997-2006

<table>
<thead>
<tr>
<th>Year</th>
<th>Breast conserving surgery (% of total)</th>
<th>Mastectomy without immediate reconstruction (% of total)</th>
<th>Mastectomy with immediate reconstruction (% of total)</th>
<th>Total number of breast cancer operations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997-98</td>
<td>14,090 (57.1)</td>
<td>9,802 (39.7)</td>
<td>792 (3.2)</td>
<td>24,684</td>
</tr>
<tr>
<td>1998-99</td>
<td>15,609 (57.2)</td>
<td>10,696 (39.2)</td>
<td>987 (3.6)</td>
<td>27,292</td>
</tr>
<tr>
<td>1999-00</td>
<td>16,146 (57.0)</td>
<td>11,066 (39.0)</td>
<td>1128 (4.0)</td>
<td>28,340</td>
</tr>
<tr>
<td>2000-01</td>
<td>15,926 (56.5)</td>
<td>11,025 (39.1)</td>
<td>1246 (4.4)</td>
<td>28,197</td>
</tr>
<tr>
<td>2001-02</td>
<td>16,150 (56.0)</td>
<td>11,417 (39.6)</td>
<td>1248 (4.3)</td>
<td>28,815</td>
</tr>
<tr>
<td>2002-03</td>
<td>17,029 (56.9)</td>
<td>11,604 (38.8)</td>
<td>1303 (4.4)</td>
<td>29,936</td>
</tr>
<tr>
<td>2003-04</td>
<td>18,258 (57.6)</td>
<td>12,044 (38.0)</td>
<td>1369 (4.3)</td>
<td>31,671</td>
</tr>
<tr>
<td>2004-05</td>
<td>18,607 (58.1)</td>
<td>12,088 (37.7)</td>
<td>1355 (4.2)</td>
<td>32,050</td>
</tr>
<tr>
<td>2005-06</td>
<td>19,962 (59.0)</td>
<td>12,291 (36.3)</td>
<td>1561 (4.6)</td>
<td>33,814</td>
</tr>
</tbody>
</table>
number of mastectomy operations increased from 9,802 to 12,291, and the number of immediate reconstruction procedures from 792 to 1,561. These changes are consistent with the significant increase in breast cancer incidence over recent years. Although the overall number of operations increased, the relative proportions remained remarkably stable. The likelihood of a woman with breast cancer undergoing breast conserving surgery, mastectomy, or mastectomy with immediate reconstruction hardly changed over the nine year period. As a proportion of all women undergoing mastectomy, the number undergoing mastectomy with immediate reconstruction has increased from 7 per cent in 1997-1998 to 11 per cent in 2005-2006.

**Delayed reconstruction surgery**

Some of the women classified as ‘mastectomy without immediate reconstruction’ below will have gone on to have a delayed reconstruction of their breast. Accurate identification of delayed reconstruction procedures is difficult within HES as one can only work forward from a confirmed mastectomy. For mastectomies performed in recent years HES will produce an underestimate of delayed reconstruction procedures as women may have such procedures up to 20 years after their original mastectomy. The most accurate estimate obtainable relates to women who had a delayed reconstruction in 2005-2006 as nine years worth of HES data can be used to identify their original mastectomy procedure. Using this method it can be estimated that around 1,000 delayed reconstructions were performed in the NHS in England in 2005-2006. This is likely to be an underestimate as:

(i) some women who had a mastectomy prior to 1997 will have had a delayed reconstruction in 2005-2006 and it is not possible to identify these women within HES

(ii) some women who had their original mastectomy outside the English NHS (e.g. in another country or in the private sector) will also have a delayed reconstruction in 2005-2006.

**Centralisation of breast cancer surgery**

Figure 3 shows the number of NHS Trusts in England that performed breast cancer surgery over the period 1997 to 2006. The number of Trusts providing breast conserving and mastectomy surgery fell by 27 per cent, but the number providing immediate reconstruction did not change. The large number of NHS Trust mergers that took place over this period may mean that the degree of

<table>
<thead>
<tr>
<th>Year</th>
<th>Trusts performing breast conserving surgery</th>
<th>Trusts performing mastectomy</th>
<th>Trusts performing immediate reconstruction</th>
<th>Trusts performing delayed reconstruction*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997-98</td>
<td>211</td>
<td>209</td>
<td>114</td>
<td>-</td>
</tr>
<tr>
<td>1998-99</td>
<td>202</td>
<td>197</td>
<td>115</td>
<td>-</td>
</tr>
<tr>
<td>1999-00</td>
<td>187</td>
<td>183</td>
<td>118</td>
<td>-</td>
</tr>
<tr>
<td>2000-01</td>
<td>180</td>
<td>178</td>
<td>111</td>
<td>-</td>
</tr>
<tr>
<td>2001-02</td>
<td>169</td>
<td>171</td>
<td>116</td>
<td>-</td>
</tr>
<tr>
<td>2002-03</td>
<td>156</td>
<td>157</td>
<td>106</td>
<td>-</td>
</tr>
<tr>
<td>2003-04</td>
<td>155</td>
<td>151</td>
<td>110</td>
<td>-</td>
</tr>
<tr>
<td>2004-05</td>
<td>153</td>
<td>152</td>
<td>109</td>
<td>-</td>
</tr>
<tr>
<td>2005-06</td>
<td>154</td>
<td>153</td>
<td>114</td>
<td>174</td>
</tr>
</tbody>
</table>

*Best estimate available only for 2005-06, may be a slight underestimate
centralisation that took place at hospital level is somewhat overstated in Figure 3.

In 2005-2006, more Trusts perform delayed breast reconstruction than any other type of breast cancer surgery. As it is undertaken after the initial cancer treatment is complete, delayed breast reconstruction can be performed without the involvement of a breast cancer MDT. This may explain why such surgery is available at a larger number of Trusts than other types of breast cancer surgery.

**Number of breast reconstruction procedures performed at each NHS Trust**

The service changes recommended within the 2000 NHS Cancer Plan aimed to ensure that patients were not treated in “low volume” Trusts for their breast cancer. This is reflected in national standards set for the minimum number of cases diagnosed and treated by an accredited breast unit annually. These national standards do not currently extend to breast reconstruction, although the 2007 oncoplastic breast surgery guidelines produced by the relevant UK surgical specialty associations state that a caseload of at least 25 major reconstructive procedures per annum should be performed in order to qualify as an oncoplastic training unit. In 2005-2006, 180 NHS Trusts provided immediate and/or delayed breast reconstruction procedures for women with a previous breast cancer diagnosis. In that year, 54 (30 per cent) of these Trusts performed less than six reconstructions. Ninety two Trusts (51 per cent) performed between 6 and 24 procedures with only 34 Trusts (19 per cent) undertaking 25 or more procedures.

**Trusts performing mastectomy but not immediate breast reconstruction**

The proportion of Trusts that performed mastectomy surgery but not immediate reconstruction fell from 95 out of 209 (46 per cent) to 39 out of 153 (26 per cent) between 1997 and 2006. Interestingly, 36 of the 39 NHS Trusts that provided mastectomy but not immediate reconstruction in 2005-2006 were able to provide delayed breast reconstruction.

**Accuracy of HES**

The above analysis assumes no systematic error in HES coding of breast cancer diagnosis and surgery. The prospective audit module of the National Mastectomy and Breast Reconstruction Audit will to some extent allow validation of HES as it will be possible to compare HES data for 2008 with clinical data collected prospectively over the same period.
9.0 Discussion

The work carried out so far has demonstrated that although there is a general perception that a good surgical service is available to women with breast cancer in England and Wales, there are considerable pressures upon the service. There are many sources of pressure.

- The rising incidence of breast cancer and the need to perform more operations.
- The requirement to provide a higher proportion of women with reconstructive options after mastectomy.
- The pressure created by cancer waiting time targets, specifically the need to perform definitive treatment within 62 days of initial referral.
- The pressure to centralise and perform surgery at high volume centres.
- The difficulty securing resources to adequately staff an MDT, provide breast reconstruction procedures and ring-fence beds, theatre time and staff.

Service providers have coped admirably in the face of these pressures, providing a 37 per cent increase in the number of operations performed over the period 1997 to 2006. The overall number of immediate reconstruction procedures provided by the English NHS almost doubled between 1997 and 2006. However, there seems to have been difficulty in implementing the 2002 NICE guidance that immediate reconstruction should be available for all women undergoing mastectomy. The proportion of all women undergoing mastectomy who received an immediate reconstruction increased only from 7 per cent to 11 per cent.

There was a significant consensus among stakeholders about the determinants of quality in breast cancer surgery. Seven themes were identified.

- Service configuration.
- Resources.
- Communication with patients.
- Time to allow informed and reasoned decision making.
- Training of staff.
- Communication between clinicians.
- Defining and auditing quality standards and outcomes.

These themes correspond to previous national guidance including the 2000 NHS Cancer Plan, the 2002 NICE guidance ‘Improving Outcomes in Breast Cancer,’ the 2007 Cancer Reform Strategy and the 2007 oncoplastic surgery guidelines from the UK surgical specialty associations. This implies a consensus among stakeholders in breast cancer surgery which is an excellent basis on which to move forward with service improvement. It is useful to consider the evidence gathered on challenges to quality of care within each theme.

Service configuration

Local access to immediate breast reconstruction is not uniform across England and Wales. Although falling in number, 39 English NHS Trusts (26 per cent) that performed mastectomy surgery in 2005-06 did not also provide immediate reconstruction as a local option according to HES. Even if these centres have formal referral arrangements with other centres, this extra step in the referral process may deter some women from having a breast reconstruction. When directly asked, 92 per cent of NHS Trusts and 82 per cent of private hospitals report that they comply with the 2002 NICE guidance on access to immediate reconstruction. However, it is not clear whether this refers to offering the option of immediate reconstruction to all women undergoing mastectomy, or to facilitating delayed reconstruction instead.

In 2005-2006, 36 NHS Trusts performed delayed breast reconstruction procedures but no immediate reconstructions. Breast reconstruction surgery, whether immediate or delayed, requires specialist surgical skills along with the ward based support required to ensure appropriate post-operative care so there is no obvious clinical reason to not provide immediate breast reconstruction at a centre where delayed reconstruction is available.

There was also considerable variation in both the NHS and private sector with respect to the use of chemotherapy before surgery to enable the offer of an immediate reconstruction. 55 per cent of NHS
 Trusts would provide the option of such therapy to a woman with metastatic disease while 45 per cent would not. 72 per cent of private hospitals said they would provide this option to women with metastatic disease. The variation observed is likely to create inequities in access to immediate breast reconstruction.

**Resources**

Breast reconstruction surgery is resource-intensive and the current funding climate within the NHS creates disincentives to increase the number of procedures performed. Indeed, there is a perception that some service commissioners deliberately create barriers to the availability of breast reconstruction such as insiting on a psychological evaluation. One way in which breast cancer centres have responded to the pressure on their resources is by ring fencing beds. To reduce the likelihood of surgery being cancelled many Trusts now “ring fence” beds for women undergoing breast cancer surgery. This means that emergency patients or those admitted by other specialties may not use these beds, as they are reserved exclusively for women undergoing mastectomy or breast reconstruction. An added advantage of having reserved beds is that the ward-based team looking after these patients become expert in their care.

**Communication with patients**

A national standard from the 2002 NICE report ‘Improving Outcomes in Breast Cancer’ is that specialist breast care nurses should be available to all patients with breast cancer, and involved as a core member of any breast cancer multi-disciplinary team. These nurses play a central role in providing information to breast cancer surgery patients and supporting them during the decision making process. They provide a key support for patients who are making decisions about breast reconstruction. It is surprising to find that 11 per cent of private hospitals providing breast cancer surgery do not meet this standard.

NHS Trusts have on average twice as many breast care nurses as private hospitals, reflecting the number of patients seen by each. However, even taking into account patient numbers, it is undesirable that some centres employ only one breast care nurse. This means that patients may be unable to access specialist nursing care if the sole nurse is away on annual or sick leave. Although only seven NHS Trusts with breast care nurses had only one such nurse, 60 private hospitals reported this staffing level.

**Time to allow informed and reasoned decision making**

The decision to proceed with immediate breast reconstruction is difficult and women require adequate time to digest the information and choices available. The window of time available to make this decision is limited by the target laid down by the 2000 NHS Cancer Plan that patients with symptomatic breast cancer should receive their definitive treatment within 62 days of referral. There is a perception that decisions about reconstruction are often relegated to a secondary concern because of the urgent need to move the patient to definitive treatment within the 62 day window.

**Training of staff**

The training provided to surgeons who perform mastectomy and breast reconstruction surgery is a key determinant of service quality. Ideally, breast surgeons should receive their training at designated oncoplastic training units which perform a relatively high number of procedures as low volume centres may provide a poor environment for surgeons to train and improve their breast reconstruction skills. One third of all the English NHS Trusts that performed breast reconstruction surgery for women performed less than six such procedures in 2005-2006, indicating that reconstruction surgery is still performed at Trusts with relatively little experience in the field. Published guidance states that a minimum of 25 breast reconstruction procedures should be performed per annum for a centre to qualify as an oncoplastic training unit. The 2007 Cancer Reform strategy also states that:

“In some places consultants are continuing to operate on very small numbers of cases... PCTs should not commission services from providers with such low volumes.” (page 101)

One encouraging development in the field of surgical training is the breakdown in surgical specialty boundaries as evidenced, for example, by
the 80 NHS Trusts who report that general surgeons with a specialty interest in breast surgery perform pedicle flap breast reconstructions. The innovative oncoplastic breast training programme established by the British Association of Plastic Reconstructive and Aesthetic Surgeons and the British Association of Surgical Oncology may have encouraged this development.

**Communication between clinicians**

A fifth of the NHS Trusts that perform breast cancer surgery do not have a consultant oncologist, pathologist or radiologist with a specialist interest in breast cancer within the Trust. This may impair the quality of diagnostic services and adjuvant (non-surgical) therapy planning for women treated at these centres. The absence of oncologists at MDT meetings may lead to difficulties identifying patients who need adjuvant radiotherapy after mastectomy, making it difficult to decide whether patients are suitable for immediate breast reconstruction. In this situation, centres may choose to defer reconstruction in all women until the final histological (pathology) diagnosis is available. It is true that many Trusts are visited by specialist breast oncologists employed elsewhere but this may still lead to delays in decision making.

94 per cent of private hospitals report that the needs of their breast cancer surgery patients are discussed at a MDT elsewhere. This may impair the quality and speed of decision making about breast reconstruction for these patients and inhibit local efforts to audit the quality of care.

**Defining and auditing quality standards and outcomes**

Most NHS Trusts and private hospitals contribute to one or more national clinical datasets on breast cancer care. However, most of these datasets contain only limited information on breast reconstruction practices and outcomes. The prospective data collection module of the National Mastectomy and Breast Reconstruction Audit aims to deal with this information deficit and all relevant service providers are strongly encouraged to participate.
10.0 Conclusions

In general, there is a perception that breast cancer surgery services in England and Wales provide a good standard of care in difficult and demanding circumstances. The rising incidence of breast cancer has created a greatly increased demand for all forms of breast cancer surgery and service providers have responded well to this demand. Yet concerns with respect to certain aspects of the service remain. The most important issue identified is inequity of access for women who want an immediate reconstruction. Despite guidance from NICE in 2002 that all women undergoing a mastectomy should have this option there has been limited progress to date. A number of barriers must be overcome before full implementation of the NICE guidance is possible.

A prospective audit of women undergoing mastectomy with and without reconstruction in England and Wales began on the 1 January 2008, and will continue until the 30 September 2008. This cohort of women will then be followed up at three and eighteen months using patient questionnaires that will assess their satisfaction with care and the quality of life outcomes attained, while gathering additional data on treatments and complications following the primary surgery. This will allow an in-depth patient level exploration of determinants of access to immediate breast reconstruction.

The results presented in this first annual report have informed both the clinical dataset and patient questionnaires to be used in the prospective audit, particularly with respect to information on the personal, clinical and organisational determinants of access to immediate reconstruction. Future annual reports will provide progressively greater information on this issue.
# Appendix 1

## Prospective Data Collection Data Sheets

### National Mastectomy & Breast Reconstruction Audit Datasheet - Mastectomy +/- Immediate Reconstruction

<table>
<thead>
<tr>
<th>Patient Registration data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surname</td>
</tr>
<tr>
<td>Forename</td>
</tr>
<tr>
<td>NHS/Private Hospital Number</td>
</tr>
<tr>
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<td>Ethnicity</td>
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</table>

<table>
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</tr>
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</tr>
<tr>
<td>□ Patient was capable but not asked whether they were happy to receive questionnaire</td>
</tr>
</tbody>
</table>

Reason patient was judged incapable of completing the questionnaires (if applicable):

- □ Poor eyesight
- □ Literacy or language comprehension problems
- □ Cognitive impairment

**DO NOT SUBMIT DATA ELECTRONICALLY UNTIL THIS SECTION IS COMPLETED**

### Previous treatment data

- Date of breast cancer diagnosis: ____________
- Date of decision to treat (mastectomy): ____________

Treatments for ipsilateral breast cancer prior to this admission (please select all that apply):

- □ None
- □ Breast-conserving surgery
- □ Axillary surgery (including Sentinel Node Bx)
- □ Radiotherapy
- □ Chemotherapy
- □ Hormone Therapy

### Co-morbidity data

Smoking status:

- □ Current smoker
- □ Ex-smoker
- □ Never smoked

ASA Grading (from pre-operative assessment):

- □ I – Normal healthy individual
- □ II – Mild systemic disease that does not limit activity
- □ III – Severe systemic disease that limits activity but is not incapacitating
- □ IV – Incapacitating systemic disease which is constantly life-threatening

Body mass index:

- Weight/kg ______
- Height/m __________
- BMI (W/H²) ________

Pre-operative performance status (ECOG/WHO):

- □ 0 - Fully active
- □ 1 - Light/office work
- □ 2 – Ambulatory / self care, up and about > 50% of the time
- □ 3 - Limited self care, confined to bed / chair > 50% waking hours
- □ 4 - Completely disabled, no self care and totally confined to bed / chair
## National Mastectomy & Breast Reconstruction Audit
### Datasheet - Mastectomy +/- Immediate Reconstruction

### Operative data

**Date of admission for surgery:**

**Date of mastectomy:**

### Type of mastectomy (please select one option only):
- Simple mastectomy
- Subcutaneous or skin sparing mastectomy via circumareolar approach (nipple excised)
- Subcutaneous or envelope mastectomy via lateral or submammary approach (nipple spared)
- Total mastectomy with excision of any part of pectoralis muscle
- Total mastectomy with excision of both pectoral muscles + part of chest wall

### Type of axillary surgery (please select one option only):
- None
- Sentinel node biopsy
- Axillary sampling
- Level 1 axillary clearance
- Level 2 axillary clearance
- Level 3 axillary clearance

### Type of immediate primary reconstruction performed (please select all that apply):
- None
- Tissue expander
- Fixed volume implant
- Latissimus Dorsi flap
- TRAM pedicle flap
- TRAM free flap
- DIEP free flap
- SIEA free flap
- TDAP flap
- TMG/TUG free flap
- SGAP free flap
- IGAP free flap
- Nipple reconstruction

### Type of contralateral symmetrisation surgery performed (please select all that apply):
- None
- Tissue expander
- Augmentation mammoplasty
- Reduction mammoplasty
- Mastopexy (skin reduction only)

### Planned adjuvant treatments: Planned secondary reconstructive procedures:
- Radiotherapy
- Chemotherapy
- Hormone therapy
- Specialist palliative care
- Tissue expansion of breast mound
- Exchange of expander for fixed volume implant
- Nipple reconstruction
- Areolar tattooing
- Symmetrisation procedure
- Exchange of implant/expander for autologous flap
### National Mastectomy & Breast Reconstruction Audit
**Datasheet - Mastectomy +/- Immediate Reconstruction**

**Reconstructive decision-making data**

**PLEASE COMPLETE IF IMMEDIATE RECONSTRUCTION HAS NOT BEEN PERFORMED**

Was immediate reconstruction offered to this patient?  □ Yes  □ No

If immediate reconstruction was not offered, why was this? (please select all that apply)

**Patient appropriateness for surgery:**
- □ Advanced stage of disease
- □ Concerns about local recurrence
- □ Age of patient
- □ Degree of co-morbidity (e.g. cardio-respiratory disease)
- □ Lifestyle factors (e.g. smoking)
- □ Cognitive impairment
- □ Mental health issues (e.g. psychiatric illness)

**Treatment pathway issues:**
- □ Patient has undergone recent neo-adjuvant chemotherapy
- □ Adjuvant radiotherapy to chest wall anticipated for this patient
- □ Reconstructive surgery would delay other anticipated adjuvant therapies

**Service access issues:**
- □ Immediate reconstruction not available locally
- □ Immediate reconstruction would significantly delay mastectomy surgery

Has delayed reconstruction been offered to this patient?  □ Yes  □ No

If yes, have they accepted the offer?  □ Yes  □ No

If delayed reconstruction has not been offered, why is this? (please select all that apply)

**Patient appropriateness for surgery:**
- □ Advanced stage of disease
- □ Concerns about local recurrence
- □ Age of patient
- □ Degree of co-morbidity (e.g. cardio-respiratory disease)
- □ Lifestyle factors (e.g. smoking)
- □ Cognitive impairment
- □ Mental health issues (e.g. psychiatric illness)

**Service access issues:**
- □ Delayed reconstruction not available locally
# National Mastectomy & Breast Reconstruction Audit

## Datasheet - Mastectomy +/- Immediate Reconstruction

### Peri-operative morbidity data

<table>
<thead>
<tr>
<th>Event</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return to theatre during admission</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency transfer to HDU or ITU during admission</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death during admission</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### In-patient complications (please select all that apply):

#### Complications requiring therapeutic intervention at:

<table>
<thead>
<tr>
<th>Complication</th>
<th>Mastectomy site</th>
<th>Flap donor site (if applicable)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
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<td>Wound infection requiring intravenous antibiotics</td>
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</tr>
<tr>
<td>Skin flap necrosis requiring surgical debridement</td>
<td></td>
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<tr>
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<td></td>
</tr>
<tr>
<td>Haematoma or seroma requiring aspiration or drainage</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Flap-related complications requiring therapeutic intervention:

<table>
<thead>
<tr>
<th>Complication</th>
<th>Mastectomy site</th>
<th>Flap donor site (if applicable)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not applicable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impaired flap perfusion requiring re-exploration or revision of anastomosis</td>
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<td></td>
</tr>
<tr>
<td>Partial flap necrosis or failure requiring debridement</td>
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<td>Total flap necrosis or failure requiring removal</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Implant/expander-related complications requiring therapeutic intervention:

<table>
<thead>
<tr>
<th>Complication</th>
<th>Mastectomy site</th>
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</tr>
</thead>
<tbody>
<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Displaced implant/expander requiring re-positioning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infected implant/expander requiring intravenous antibiotic therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infected implant/expander requiring removal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ruptured implant/expander requiring removal</td>
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</tbody>
</table>

#### Distant or systemic complications requiring therapeutic intervention:

<table>
<thead>
<tr>
<th>Complication</th>
<th>Mastectomy site</th>
<th>Flap donor site (if applicable)</th>
</tr>
</thead>
<tbody>
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<td>None</td>
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<td>Deep venous thrombosis (DVT) requiring formal anticoagulation</td>
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<td></td>
</tr>
<tr>
<td>Pulmonary embolism (PE) requiring formal anticoagulation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute myocardial infarction (MI) requiring anticoagulation +/- thrombolysis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## National Mastectomy & Breast Reconstruction Audit
### Datasheet - Mastectomy +/- Immediate Reconstruction

<table>
<thead>
<tr>
<th>Pathology data (from post-operative histology report)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumour laterality: □ Right □ Left</td>
</tr>
<tr>
<td>Invasive status: □ Invasive □ DCIS (ductal carcinoma in situ)</td>
</tr>
</tbody>
</table>

**Grade of DCIS or Invasive Carcinoma:**
- □ 1 – low (DCIS) or well differentiated (invasive)
- □ 2 – intermediate (DCIS) or moderately differentiated (invasive)
- □ 3 – high (DCIS) or poorly differentiated (invasive)

**Lymph node involvement:**

(_______ / _______)

(number of positive axillary nodes / total number of axillary nodes in pathology specimen)

**Invasive lesion size (mm):** _________

**Recorded Nottingham Prognostic Index Score (if invasive):** _________
## National Mastectomy & Breast Reconstruction Audit
### Datasheet – Delayed Reconstruction

### Patient Registration data

<table>
<thead>
<tr>
<th>Surname</th>
<th>Forename</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>NHS/Private Hospital Number</th>
<th>Date of birth</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Postcode</th>
<th>Ethnicity</th>
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### Patient-reported outcomes consent

**Has this patient consented to being sent outcome questionnaires?**

- [ ] Patient has consented to receive questionnaires
- [ ] Patient does not want to receive questionnaires
- [ ] Patient judged incapable of completing a written questionnaire in English
- [ ] Patient was capable but not asked whether they were happy to receive questionnaire

### Reason patient was judged incapable of completing the questionnaires (if applicable):

- [ ] Poor eyesight
- [ ] Literacy or language comprehension problems
- [ ] Cognitive impairment

**DO NOT SUBMIT DATA ELECTRONICALLY UNTIL THIS SECTION IS COMPLETED**

### Previous treatment data

**Date of breast cancer diagnosis:**

**Date of original mastectomy:**

### Treatments for ipsilateral breast cancer prior to this admission (please select all that apply):

- [ ] None
- [ ] Breast-conserving surgery
- [ ] Axillary surgery (including Sentinel Node Bx)
- [ ] Radiotherapy
- [ ] Chemotherapy
- [ ] Hormone Therapy

### Co-morbidity data

#### Smoking status:

- [ ] Current smoker
- [ ] Ex-smoker
- [ ] Never smoked

#### Body mass index:

<table>
<thead>
<tr>
<th>Weight/kg</th>
<th>Height/m</th>
<th>BMI (W/H(^2))</th>
</tr>
</thead>
</table>

#### Diabetes status:

- [ ] Not diabetic
- [ ] Type I diabetes
- [ ] Type II diabetes

### ASA Grading (from pre-operative assessment):

- [ ] I – Normal healthy individual
- [ ] II – Mild systemic disease that does not limit activity
- [ ] III – Severe systemic disease that limits activity but is not incapacitating
- [ ] IV – Incapacitating systemic disease which is constantly life-threatening

### Pre-operative performance status (ECOG/WHO):

- [ ] 0 - Fully active
- [ ] 1 - Light/office work
- [ ] 2 – Ambulatory / self care, up and about > 50% of the time
- [ ] 3 - Limited self care, confined to bed / chair > 50% waking hours
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### National Mastectomy & Breast Reconstruction Audit
**Datasheet – Delayed Reconstruction**

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| Grade of DCIS or Invasive Carcinoma:                  |
| □ 1 – low (DCIS) or well differentiated (invasive)    |
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| □ 3 – high (DCIS) or poorly differentiated (invasive) |

| Lymph node involvement:                               |
| (________ / ________)                                  |
| (number of positive axillary nodes / total number of axillary nodes in pathology specimen) |

| Invasive lesion size (mm):                            |
| ________                                            |

| Recorded Nottingham Prognostic Index Score (if invasive): |
| ________                                                |

### Delayed reconstruction data

| Date of admission for surgery:                        |
| ________________________                                |

| Date of delayed reconstruction:                        |
| ________________________                                |

| Type of delayed primary reconstruction performed (please select all that apply): |
| □ Tissue expander                                       |
| □ SIEA free flap                                         |
| □ Fixed volume implant                                   |
| □ TDAP flap                                              |
| □ Latissimus Dorsi flap                                  |
| □ TMG/TUG free flap                                      |
| □ TRAM pedicle flap                                      |
| □ SGAP free flap                                         |
| □ TRAM free flap                                         |
| □ IGAP free flap                                         |
| □ DIEP free flap                                         |
| □ Nipple reconstruction                                  |

| Type of contralateral symmetrisation surgery performed (please select all that apply): |
| □ None                                                   |
| □ Reduction mammoplasty                                 |
| □ Tissue expander                                       |
| □ Mastopexy (skin reduction only)                        |
| □ Augmentation mammoplasty                               |

| Planned secondary reconstructive procedures:            |
| □ Tissue expansion of breast mound                      |
| □ Exchange of expander for fixed volume implant         |
| □ Nipple reconstruction                                 |
| □ Areolar tattooing                                     |
| □ Symmetrisation procedure                              |
| □ Exchange of implant/expander for autologous flap      |
Appendix 1
Prospective Data Collection Data Sheets

National Mastectomy & Breast Reconstruction Audit
Datasheet – Delayed Reconstruction

Reconstructive decision-making data

Was immediate reconstruction originally offered to this patient?  □ Yes  □ No

If immediate reconstruction was not offered, why was this? (please select all that apply)

Patient appropriateness for surgery (at time of mastectomy):

☐ Advanced stage of disease
☐ Concerns about local recurrence
☐ Age of patient
☐ Degree of co-morbidity (e.g. cardio-respiratory disease)
☐ Lifestyle factors (e.g. smoking)
☐ Cognitive impairment
☐ Mental health issues (e.g. psychiatric illness)

Treatment pathway issues (at time of mastectomy):

☐ Patient has undergone recent neo-adjuvant chemotherapy
☐ Adjuvant radiotherapy to chest wall anticipated for this patient
☐ Reconstructive surgery would delay other anticipated adjuvant therapies

Service access issues (at time of mastectomy):

☐ Immediate reconstruction not available locally
☐ Immediate reconstruction would have significantly delayed mastectomy surgery
### National Mastectomy & Breast Reconstruction Audit
#### Datasheet – Delayed Reconstruction

**Peri-operative morbidity data**

**Date of discharge:**

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**In-patient complications (please select all that apply):**

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**Implant/expander-related complications requiring therapeutic intervention:**

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<tbody>
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<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>None</td>
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<td>[ ]</td>
</tr>
<tr>
<td>Displaced implant/expander requiring re-positioning</td>
<td>[ ]</td>
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<td>[ ]</td>
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<tr>
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</table>

**Distant or systemic complications requiring therapeutic intervention:**

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Appendix 2

Organisational Representatives

National Mastectomy and Breast Reconstruction Audit Project Board

- Martin Old, Project Board Executive, The NHS Information Centre
- Jan van der Meulen, Senior Supplier, CEU at RCS
- Steve Dean, Senior Supplier, CEU at RCS
- Hugh Bishop, Senior User, ABS at BASO
- Venkat Ramakrishnan, Senior User, BAPRAS
- Helen Laing, Commissioner, Healthcare Commission

National Mastectomy and Breast Reconstruction Audit Clinical Reference Group

- Dick Rainsbury – Chair
- Tracy Philip and Sneh Khemka – Independent Hospitals
- Chris Holcombe – ABS at BASO
- Eva Weiler-Mithoff and Elaine Sassoon – BAPRAS
- Maria Noblet – RCN
- Kate Jones and Helen Mcleod - Chartered Society of Physiotherapy
- Dr Janet Litherland - Royal College of Radiologists
- Peter J Venn - The Royal Society of Anaesthetists
- Emma Pennary and Hannah Saul – Cancer Charities
- Lucy Elliss-Brookes – Cancer Networks
- Di Riley – Cancer Action Team
- Gill Lawrence - Cancer Registries
- Ian Monypenny – Wales
- Gillian Ross – Clinical Oncologist
The following organisations provided a response to the organisational audit. Only responses received before the deadline have been included in the analysis. Some units have reorganised since replying to the organisational questionnaire. The names given at the time of response have been used in this report.

**NHS TRUSTS**

Aintree Hospitals NHS Trust  
Airedale NHS Trust  
Ashford and St Peter’s Hospitals NHS Trust  
Barking, Havering and Redbridge Hospitals NHS Trust  
Barnet and Chase Farm Hospitals NHS Trust  
Barnsley Hospitals NHS Foundation Trust  
Barts and the London NHS Trust  
Basildon and Thurrock University Hospitals NHS Foundation Trust  
Bedford Hospital NHS Trust  
Blackpool, Fylde and Wyre Hospitals NHS Trust  
Bolton Hospitals NHS Trust  
Bradford Teaching Hospitals NHS Foundation Trust  
Brighton and Sussex University Hospitals NHS Trust  
Bro Morgannwg NHS Trust  
Bromley Hospitals NHS Trust  
Buckinghamshire Hospitals NHS Trust  
Burton Hospitals NHS Trust  
Cambridge University Hospitals NHS Foundation Trust  
Cardiff and Vale NHS Trust  
Carmarthenshire NHS Trust  
Ceredigion and Mid Wales NHS Trust  
Chelsea and Westminster Healthcare NHS Trust  
Chesterfield Royal Hospital NHS Foundation Trust  
City Hospitals Sunderland NHS Foundation Trust  
Clatterbridge Centre for Oncology NHS Trust  
Conwy and Denbighshire NHS Trust  
Countess of Chester Hospital NHS Foundation Trust  
County Durham and Darlington Acute Hospitals NHS Trust  
Dartford and Gravesham NHS Trust  
Doncaster and Bassetlaw Hospitals NHS Foundation Trust  
Dudley Group of Hospitals NHS Trust  
East and North Hertfordshire Hospitals NHS Trust  
East Cheshire NHS Trust  
East Lancashire Hospitals NHS Trust  
East Sussex Hospitals NHS Trust  
Essex Rivers Healthcare NHS Trust  
Frimley Park Hospital NHS Foundation Trust  
Gateshead Health NHS Foundation Trust  
George Eliot Hospital NHS Trust  
GloUCEstershire Hospitals NHS Foundation Trust  
Good Hope Hospital NHS Trust  
Guy’s and St Thomas’ NHS Foundation Trust  
Gwent Healthcare NHS Trust  
Heatherwood and Wexham Park Hospitals NHS Trust  
Hereford Hospitals NHS Trust  
Hinchinbrooke Health Care NHS Trust  
Homerton University Hospital NHS Foundation Trust  
Hull and East Yorkshire Hospitals NHS Trust  
Imperial College Healthcare NHS Trust  
Isle of Wight Healthcare NHS Trust
Appendix 3

Contributing Organisations

JAMES PAGET HEALTHCARE NHS TRUST
KETTERING GENERAL HOSPITAL NHS TRUST
KING’S COLLEGE HOSPITAL NHS TRUST
KINGSTON HOSPITAL NHS TRUST
LANCASHIRE TEACHING HOSPITALS NHS FOUNDATION TRUST
LEEDS TEACHING HOSPITALS NHS TRUST
LUTON AND DUNSTABLE HOSPITAL NHS TRUST
MAIDSTONE AND TUNBRIDGE WELLS NHS TRUST
MAYDAY HEALTHCARE NHS TRUST
MID ESSEX HOSPITAL SERVICES NHS TRUST
MID STAFFORDSHIRE GENERAL HOSPITALS NHS TRUST
MID YORKSHIRE HOSPITALS NHS TRUST
MILTON KEYNES GENERAL HOSPITAL NHS TRUST
NORFOLK AND NORWICH UNIVERSITY HOSPITAL NHS TRUST
NORTH BRISTOL NHS TRUST
NORTH CHESHIRE HOSPITALS NHS TRUST
NORTH CUMBRIA ACUTE HOSPITALS NHS TRUST
NORTH EAST WALES NHS TRUST
NORTH GLAMORGAN NHS TRUST
NORTH HAMPSHIRE HOSPITALS NHS TRUST
NORTH MIDDLESEX UNIVERSITY HOSPITAL NHS TRUST
NORTH TEES AND HARTLEPOOL NHS TRUST
NORTH WEST WALES NHS TRUST
NORTHAMPTON GENERAL HOSPITAL NHS TRUST
NORTHERN DEVON HEALTHCARE NHS TRUST
NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST
NORTHUMBRIA HEALTH CARE NHS TRUST
NOTTINGHAM CITY HOSPITAL NHS TRUST
OXFORD RADCLiffe HOSPITALS NHS TRUST
PEMBROKE And DERWEN NHS TRUST
PENNINE ACUTE HOSPITALS NHS TRUST
PETERBOROUGH AND STAMFORD NHS FOUNDATION TRUST
PLYMOUTH HOSPITALS NHS TRUST
PONTYPRIDD AND RHONDDA NHS TRUST
POOLE HOSPITAL NHS TRUST
PORTSMOUTH HOSPITALS NHS TRUST
QUEEN ELIZABETH HOSPITAL NHS TRUST
QUEEN MARY’S SIDCUP NHS TRUST
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ROYAL UNITED HOSPITAL BATH NHS TRUST
ROYAL WEST SUSSEX NHS TRUST
SALISBURY FOUNDATION NHS TRUST
SANDWELL AND WEST BIRMINGHAM HOSPITALS NHS TRUST
SCARBOROUGH And NORTH EAST YORKSHIRE NHS TRUST
SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST
SHERWOOD FOREST HOSPITALS NHS TRUST
SOUTH DEVON HEALTH CARE NHS TRUST
SOUTH MANCHESTER UNIVERSITY HOSPITALS NHS TRUST
SOUTH TEES HOSPITALS NHS TRUST
SOUTH TYNESIDE NHS FOUNDATION TRUST
Appendix 3

Contributing Organisations

SOUTH WARWICKSHIRE GENERAL HOSPITALS NHS TRUST
SOUTHAMPTON UNIVERSITY HOSPITALS NHS TRUST
SOUTHEND HOSPITAL NHS TRUST
SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST
ST GEORGE'S HEALTHCARE NHS TRUST
ST HELENS AND KNOWSLEY HOSPITALS NHS TRUST
SURREY AND SUSSEX HEALTHCARE NHS TRUST
SWANSEA NHS TRUST
SWINDON AND MARLBOROUGH NHS TRUST
TAUNTON AND SOMERSET NHS TRUST
THE HILLINGDON HOSPITAL NHS TRUST
THE MID CHESHIRE HOSPITALS NHS TRUST
THE NEWCASTLE UPON TYNE HOSPITALS NHS TRUST
THE PRINCESS ALEXANDRA HOSPITAL NHS TRUST
THE QUEEN ELIZABETH HOSPITAL KING'S LYNN NHS TRUST
THE ROTHERHAM NHS FOUNDATION TRUST
THE ROYAL MARSDEN NHS FOUNDATION TRUST
THE ROYAL WOLVERHAMPTON HOSPITALS NHS TRUST
THE WHITTINGTON HOSPITAL NHS TRUST
TRAFFORD HEALTHCARE NHS TRUST
UNITED BRISTOL HEALTHCARE NHS TRUST
UNITED LINCOLNSHIRE HOSPITALS NHS TRUST
UNIVERSITY HOSPITAL BIRMINGHAM NHS FOUNDATION TRUST
UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST
UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS
UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST
UNIVERSITY HOSPITALS OF MORECAMBE BAY NHS TRUST
VELINDRE NHS TRUST
WALSALL HOSPITALS NHS TRUST
WEST DORSET GENERAL HOSPITALS NHS TRUST
WEST HERTFORDSHIRE HOSPITALS NHS TRUST
WEST MIDDLESEX UNIVERSITY HOSPITAL NHS TRUST
WEST SUFFOLK HOSPITALS NHS TRUST
WESTON AREA HEALTH NHS TRUST
WHIPPS CROSS UNIVERSITY HOSPITAL NHS TRUST
WINCHESTER AND EASTLEIGH HEALTHCARE NHS TRUST
WORCESTERSHIRE ACUTE HOSPITALS NHS TRUST
WORTHING AND SOUTHLANDS NHS HOSPS FOUNDATION TRUST
YEOVIL DISTRICT HOSPITAL NHS FOUNDATION TRUST
YORK HOSPITALS NHS TRUST

INDEPENDENT ORGANISATIONS

ABBEY CALDEW HOSPITAL
ABBEY SEFTON HOSPITAL
BISHOPS WOOD HOSPITAL
BLACKHEATH HOSPITAL
BMI - BATH CLINIC
BMI - CHATSWORTH SUITE
BMI - CHELSFIELD PARK HOSPITAL
BMI - FAWKHAM MANOR HOSPITAL
BMI - GORING HALL HOSPITAL
BMI - MOUNT ALVERNIA HOSPITAL
BMI - SARUM ROAD HOSPITAL
BMI - THE ALEXANDRA HOSPITAL
BMI - THE BEARDWOOD HOSPITAL
BMI - THE CHAUCER HOSPITAL
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BMI - THE DROITWICH SPA HOSPITAL
## Appendix 3
### Contributing Organisations

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**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 (e.g. chemotherapy, radiotherapy, hormone drug therapy) provided to improve the effectiveness of the primary treatment (e.g. 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.

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

**Breast reconstruction surgery** - The surgical recreation of the breast mound (or shape) after some or all of this has been lost or removed (e.g. 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.

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

**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.

**Free flap breast reconstruction** - The breast mound (or shape) is reconstructed using the patient’s own tissue (e.g. 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.

**Healthcare Commission** - The Healthcare Commission is the independent watchdog for healthcare in England. They aim to promote improvement in the services provided by the NHS and independent healthcare organisations.

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

**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** - 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.

**Lumpectomy** - A surgical procedure to remove a discrete lump or abnormal area of tissue from the breast.

**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.
**Glossary**

**Mammography** - An imaging modality that uses x-rays to show abnormalities and structure of a breast.

**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.

**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.

**NCASP** - The National Clinical Audit Support Programme 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.

**Neo-adjuvant chemotherapy** - Chemotherapy given before another treatment, usually surgery. This is usually given to reduce the size, grade or stage of the cancer and therefore improve the effectiveness of the surgery performed.

**Neoplasm** - A neoplasm or tumour is an abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Neoplasms may be benign (not cancerous), or malignant (cancerous).

**NICE** - The National Institute of 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.

**PEDW** - Patient Episode Database Wales contains data on all in-patients treated within NHS Trusts in Wales. This includes details of admissions, diagnoses and those treatments undergone.

**Peri-operative period** - The time period surrounding a patient’s surgical procedure.

**Project Board** - The audit’s Project Board consists of senior representatives of the key stakeholders and the Healthcare Commission, 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 to design, implement, analyse and report on 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.

**STATA 9.2** - A statistical analysis software package used in our analyses.

**Tumour ablation** - The destruction or removal of a tumour using surgical or non-surgical methods.

**Ultrasound** - A imaging modality that uses high frequency sound waves to create an image of tissues or organs in the body.
References


The NHS Information Centre is working to make information more relevant and accessible to the public, regulators, health and social care professionals and policy makers, leading to improvements in knowledge and efficiency. The NHS Information Centre is an NHS special health authority that collects, analyses and distributes data to reduce the burden on frontline staff, releasing more time for direct care.

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