

June 2018

Rebuilding my body

Breast reconstruction

in England



breast cancer
now

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A message from our Chief Executive

For some women, reconstructive surgery forms an essential part of their breast cancer treatment. While advances in therapy are now seeing more women survive the disease than ever before, the impact of breast surgery on a woman's body and confidence can be profound and life-long – and this must not be underestimated.

Too often, reconstructive surgery can be dismissed as a cosmetic issue in the face of a potentially life-threatening diagnosis. This simply cannot continue. We know it can have a significant psychological impact as patients try to adjust to life after a breast cancer diagnosis, because their breasts can be fundamental to their body image, sexuality and self-esteem.

Following concerns raised about emerging variation in access to this vital option on the NHS, we set out to gain a fuller picture of the availability of reconstructive services for patients across England.

But we could not do this alone; our thanks go to the many patients who took the time to respond to our survey, the Association of Breast Surgery and British Association of Plastic Reconstructive and Aesthetic Surgeons for their valuable

contributions, and the wonderful women you'll hear from in this report, who were so forthcoming and helpful in discussing the very personal realities of life during and after treatment.

Unfortunately, our findings are deeply concerning. With reconstructive surgery known to play such an integral role in treatment, recovery and ongoing quality of life for some, it is totally unacceptable to discover that women are being denied this opportunity in some areas of the country by the introduction of new restrictive policies.

We believe that, if we all act now, by 2050 everybody who develops breast cancer will live – and live well. To achieve this ambitious goal, we urgently need to invest in research to prevent and treat the spread of the disease – but we also need to do all we can to ensure every patient is given the best possible quality of life.

Unfortunately, we believe these restrictions are categorically not in the best interest of breast cancer patients and this critical report delivers five key recommendations to Clinical Commissioning Groups (CCGs) in England of ways they may better support their patients when considering and undergoing reconstructive surgery following a mastectomy.

Our hope is that this report will challenge CCGs to consider their existing policies and practice, identify improvements and restore fair access to breast surgery services for patients across England, regardless of where they live.

We need a system that will not only allow patients to be fully involved in decisions about their treatment, but enable a more fluid pathway through surgery at an already difficult time, helping improve physical and psychological wellbeing and enabling all patients to live well with and beyond breast cancer.



Baroness Delyth Morgan
Chief Executive
Breast Cancer Now

Our hope is that this report will challenge CCGs to consider their existing policies and practice, identify improvements and restore fair access to breast surgery services for patients across England, regardless of where they live.



Introduction

A diagnosis of breast cancer can be devastating and, for many women and their families, the first thoughts are of survival and getting through treatment.

However, with more women than ever before surviving breast cancer¹, priorities often quickly turn to life after cancer. Breast Cancer Now's ambition is that, if we all act now, by 2050 everyone who develops breast cancer will live – and live well. For women who choose it, breast reconstruction can help them to move on from a diagnosis of cancer and ensure that they are able to live well, by restoring a crucial component of their body image, self-esteem and sexuality². This opportunity is being restricted in some parts of England. In these areas, patients are being denied the opportunity to have their reconstruction surgery at a time that is appropriate for them, or are being told they are only allowed a certain number of operations. We are also concerned that some patients who have breast reconstruction are being denied reduction surgery to the unaffected breast to achieve symmetry.

Breast reconstruction is not a new procedure, and international and UK guidelines have provided guidance on the provision of this service for many years. Breast cancer treatment, including reconstructive surgery techniques, has progressed significantly in recent years. However, while it may be possible to complete breast reconstruction in fewer procedures than previously, placing restrictions on the time in which reconstructive surgery needs to be complete and balancing surgery for women who choose breast reconstruction must be considered a retrograde step which is not in the best interests of patients. Breast reconstruction must never be considered to be a cosmetic procedure, regardless of when in the treatment pathway a patient decides to have it.

Reducing unwarranted variation in the NHS is a current priority and is being addressed through the Getting It Right First Time (GIRFT) programme³. The programme is led by clinical experts and aims to share best practice in order to improve patient care and

outcomes as well as delivering efficiencies in the NHS by reducing unnecessary procedures, thus saving costs. Breast surgery is one of the workstreams of this programme, which is endorsed by the Association of Breast Surgery (ABS).

Breast Cancer Now has conducted new research into the availability of breast reconstruction surgery and has found that some Clinical Commissioning Groups (CCGs) in England are restricting access to this surgery. Since 2012, 22.6% of CCGs have introduced official policies restricting breast reconstruction surgery while a further 4.3% have policies that are either informal or in draft form (at the time of writing). In each of these cases, breast reconstruction is being restricted in one of three ways:

- **A limit on the number of surgeries a patient can have to complete breast reconstruction.**
- **A limit on the time in which breast reconstruction must be complete.**

- **Denying access to balancing surgery on the unaffected breast for women who have breast reconstruction.**

This report aims to investigate the extent of these restrictions and to emphasise the importance of access to breast reconstruction to many women undergoing breast cancer treatment. Breast Cancer Now, along with the ABS and the British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS) has published guidelines to support CCGs in planning provision of breast reconstruction surgery¹⁹. By doing this we hope we can ensure that all patients have access to the breast reconstruction surgery that is right for them, regardless of where they live.

This report makes the following five recommendations to CCGs to ensure that patients have access to the breast reconstruction surgery they need (see box right).

All CCGs should:

Ensure that patients who need breast reconstruction have access to the surgery they need, when they need it, by adopting the ABS guidelines and ensuring that unwarranted variation in breast reconstruction is avoided.

Provide all healthcare professionals involved in discussing breast reconstruction with patients with adequate training and support, to ensure that patients are aware of the full range of options available to them and have realistic expectations of breast reconstruction.

Provide patients and clinicians with shared decision making tools to help them to make decisions that are in the best interests of patients.

Ensure that all patients are offered appropriate and timely psychological support and counselling to help them to make a decision about breast reconstruction.

Show all patients photos of reconstructed breasts to help them to have realistic expectations of what breast reconstruction can achieve.

While this report speaks primarily about women with breast cancer, many of the themes will also be relevant to men with breast cancer. Clinicians should consider the recommendations of this report when discussing breast reconstruction with all of their patients.

About breast reconstruction

Breast reconstruction refers to rebuilding the breast after breast surgery, and is most common for women who have had a mastectomy. After mastectomy, there are two main ways in which breast reconstruction is carried out – using an implant or using tissue from another part of the body.

Implant reconstruction is a relatively simple procedure and is carried out by inserting an implant under or over the chest muscle. Although this is a simpler operation, patients may find that the reconstructed breast does not feel or look natural⁴.

The alternative is to create a breast shape using a piece of tissue taken from another part of the body, usually the back or abdomen. This method has the advantage that the reconstructed breast may have a more natural feel than an implant, but it does involve more complicated surgery and causes more scars. There may also be additional problems in the area the tissue is taken from, such as an increased risk of developing a hernia when tissue is taken from the abdomen⁴.

Rebuilding my body Victoria's story

I was diagnosed with stage 1 breast cancer in 2014 – it was a total shock to the system. I met with my surgeon a week after I was diagnosed, and knew at that point I wanted a double mastectomy and reconstruction as I believed it would reduce the risk of my cancer returning. Luckily he respected my wishes, and didn't try to talk me out of anything. I had six rounds of chemotherapy beforehand, then my surgery in February 2015 – I went for implants with bio-tissue mesh.

I had the best possible care I could've imagined. My surgeon left my nipples intact and the sensation in my breasts has even come back. I go swimming with my girls, wear a bikini and feel I have nothing to hide. I'm so happy with how I look- I feel like a woman again.

For reconstruction after breast conserving surgery, the surgeon can reshape a smaller breast using what tissue remains after the cancer has been removed or re-shape the breast using tissue from another part of the body⁴.

A reconstructed breast may not match the unaffected breast in size and shape. In these cases, women should be offered surgery on the unaffected breast to match it to the reconstructed breast. This may involve increasing or decreasing the size of the breast, or changing the shape. During breast surgery the nipple may need to be removed. This can be reconstructed as well – this is usually the last part of the breast reconstruction process⁴.



It is totally unacceptable to discover that women are being denied this opportunity in some areas of the country by the introduction of new restrictive policies.

Guidelines from the National Institute for Health and Care Excellence (NICE), which have been in place since 2009, state that immediate breast reconstruction should be offered to all patients who have had a mastectomy and that this option should be offered to all eligible patients unless the patient has significant other conditions or is due to have additional treatment which would impact on the effectiveness of immediate reconstruction⁵. In addition, clinical advice issued by NHS England's Breast Cancer Clinical Expert Group states that all patients who have breast reconstruction and those who have breast conserving surgery which results in a smaller breast should also have the option of balancing surgery to the unaffected breast⁶.

The UK is not alone in this recommendation - international guidelines also state that all women should be offered breast reconstruction.

The European Society for Medical Oncology (ESMO) guidelines suggest that, while not all women will be suitable for immediate reconstruction, for those for whom it is suitable, immediate reconstruction can make the prospect of losing a breast easier to cope with⁷. They also state that patients may prefer to decline or delay breast reconstruction due to personal preference. However, there is no evidence for routinely waiting 1-2 years after mastectomy before offering breast reconstruction, which is an outdated practice⁷. In Canada, it has been suggested that a lack of useful guidelines about breast reconstruction may be a genuine barrier to reconstruction and may lead to variation between centres offering this service⁸. Australian guidelines highlight the importance of women having time to consider breast reconstruction so that they are able to weigh up the advantages and disadvantages and make an informed decision⁹.

The psychological importance of breast reconstruction

While the majority of women choose not to have breast reconstruction, for those who choose it, it is an essential part of their treatment for breast cancer.

The National Mastectomy and Breast Reconstruction Audit was published in 2011 and collected details of women who underwent mastectomy and breast reconstruction between 1 January 2008 and 31 March 2009. The audit covered all 150 NHS acute trusts and England, as well as 114 independent sector hospitals and six NHS trusts in Wales and Scotland. The audit looked at 16,487 women who had a mastectomy during the audit period. 21% of women had immediate reconstructive surgery with 10% undergoing delayed breast reconstruction¹⁰.

The audit followed up with women 18 months after surgery to ask about their satisfaction with the results of their surgery as well as about their physical, emotional and sexual wellbeing. These responses were then split into women who had mastectomies, those who had immediate reconstructions and those who had delayed reconstructions.

The audit found a difference in the patient outcomes between the three groups, with the starkest differences seen in response to questions about sex and intimacy. When asked how often they felt confident sexually, 34% of women who had mastectomy without reconstruction answered most or all of the time, compared to up to 60% of those who had immediate or delayed breast reconstruction.

When asked how often they felt sexually attractive when unclothed, 15% of women who had a mastectomy without reconstruction answered most or all of the time, compared to 47% of those who had immediate or delayed breast reconstruction¹⁰. Breast reconstruction is helping these women to live well after a diagnosis of breast cancer.

For many patients, the psychological impact of breast reconstruction is significant. Breasts can form an essential part of a woman's body image, self-esteem and sexuality and women may choose to have breast reconstruction for these reasons. Women may also feel that their breasts are important to their partner (if they have one) and help them to feel confident during sex and intimacy and choose reconstruction for that reason¹⁰. Some women feel that breast reconstruction will help them to regain their body shape and therefore normality in their lives¹¹. In addition, women who are not satisfied with their breast reconstruction may avoid intimate situations or certain clothing choices as they are not confident with how their body looks¹¹.

For many patients, the psychological impact of breast reconstruction is significant.

'I hate the way I look. I have no self confidence in my body and have not had sex since before my mastectomy. I feel that I would disgust someone once I am naked.'

**Breast cancer patient
35-44
West Midlands**

Mastectomy to the unaffected breast

Women who choose not to have breast reconstruction will be offered breast prostheses which can be inserted into a bra or stuck to the skin⁴.

Breast prostheses help to even up the size and shape of breasts under clothing. Some women find breast prostheses to be uncomfortable and therefore a small number of women may request a mastectomy to the unaffected breast (a contralateral mastectomy) instead of using breast prostheses. Unless a patient has an increased risk of recurrence due to a significant family history of breast cancer, mastectomy to the unaffected breast is not medically necessary and is not recommended as it is unlikely to provide a survival benefit¹³. It is for this reason that a contralateral mastectomy is not routinely offered to women without a significant family history of breast cancer and many surgeons will be reluctant to remove a healthy breast.

While this is an important issue for some patients, it is important to recognise that this procedure is not routinely offered for medical reasons rather than because CCGs are restricting the surgery that they offer to patients. In 2017, Breast Cancer Now carried out a survey of patients who have had surgery for breast cancer in the last five years¹².

Rebuilding my body Sheena's story

I was diagnosed with stage 2 breast cancer in May 2015. My surgeon initially wanted me to have a lumpectomy, but my preference was for a mastectomy and as it turned out, I needed one anyway.

I had breast cancer symptoms and attended several appointments with specialists over a few years, but my breast cancer was not picked up on scans. When I finally received my diagnosis, I was told my cancer had been growing for a long time.

Each time I met with my surgeon, I asked for a mastectomy to remove my unaffected breast. I felt that after chemotherapy, surgery and tamoxifen, I needed to regain control of my cancer and my future. However, my surgeon was not supportive of this course of action as she said she did not wish to remove a healthy breast. I reminded the surgeon that I had been told my affected breast was healthy tissue when it wasn't.

Finally, after a year had passed, I happened to see a different surgeon who agreed to carry out the mastectomy on my unaffected breast. I felt that psychological support was not available throughout my treatment and I had to seek this out myself from charities. I find it much easier being flat than lopsided and I feel that this mastectomy has helped to give me some closure on my cancer.

Out of 578 women who answered questions about the type of breast surgery they had, 20% had mastectomy only, 15% had mastectomy with immediate reconstruction and 10% had mastectomy with delayed

reconstruction. Smaller numbers of patients had a double mastectomy with or without reconstruction (either because they had cancer in both breasts or requested a contralateral mastectomy to the unaffected breast).



Breast Cancer Now believes that women should be supported to make a decision that is right for them.

The remaining respondents had breast conserving surgery, either with or without balancing surgery to the unaffected breast.

46 women responding to our survey had requested mastectomies to the unaffected breast. When asked why they had requested this surgery, 66% of respondents said it was to achieve balance. 41% of respondents said they believed it would reduce their risk of breast cancer occurring in their unaffected breast and 37% said they didn't want to wear a prosthetic breast. Only 10% of respondents said that they had a family history of breast cancer.

Many women who requested a contralateral mastectomy were told that they would need to have counselling or psychological assessments in order to go through with this operation, unless they have an increased risk of recurrence because of their family history or type of breast cancer. The ABS has previously published a statement about provision of mastectomy to the unaffected breast for women who have breast cancer in one breast only.

This statement advises that women should be counselled about the risks of having this surgery and that in most women, it is not considered to be medically necessary. However, while this statement acknowledges that not all CCGs will fund this procedure, it acknowledges that it may be appropriate in some circumstances¹³. Breast Cancer Now believes that women should be supported to make a decision that is right for them and it is therefore essential that counselling and psychological support are available to women in a timely manner to allow them to make that decision without delaying their treatment. A mastectomy to the unaffected breast should be provided to women who have been supported appropriately to make this decision for themselves.

Patient involvement in breast reconstruction planning

Research has shown that it is common for women who undergo breast reconstruction to regret their decision. Sheehan et al (2008) found that 47.1% of women experienced mild or moderate to strong regret over their decision to have reconstructive surgery and that women experienced the same levels of regret whether they had immediate or delayed reconstruction.

This study found that women who felt negatively about their body image were more likely to experience moderate to strong levels of regret, feeling either that they had made a poor decision or that a better result would have been possible with a different decision.

Sheehan et al also suggested that, for some women, regret may be caused by unrealistic expectations of the aesthetic outcomes of breast reconstruction¹⁴. This can result in patients seeking further surgery, which can increase patient anxiety levels and may not increase their levels of satisfaction in the outcome.

To help reduce regret experienced by women after breast reconstruction, it is crucial that patients have access to the information they need to make a decision that is right for them.

Rebuilding my body Louise's story

I was first diagnosed with stage 2 breast cancer in September 2014, aged 34. My surgeon initially explained he wanted to do a lumpectomy, however I considered all my options, including my views of my risk of recurrence, and discussed this with a psychologist. I then decided I'd rather have a mastectomy, which my surgeon agreed to carry out.

I was unsure whether I wanted to have a DIEP or TRAM flap reconstruction, but knew both would involve extensive surgery. I was also sure that I didn't want an implant reconstruction, so I opted to defer the surgery until I'd reached a final resolution in my own mind.

My surgeon was surprised that I was happy to be left flat on one side, but was respectful of my decision and reiterated that it was my choice and that I could go back for the reconstructive surgery in a few months, a few years or whenever I decided to. I'm still flat on my mastectomy side three years later, and I don't know whether I'll ever have the reconstruction done. Opening old wounds doesn't feel like a natural progression to me. But I'd like to have the option should I choose to.

For most women, breast reconstruction will be a process rather than a single operation and they will need to return for additional operations⁶.

It is important that surgeons are able to assist with this decision-making process by discussing the potential benefits and risks of reconstructive surgery and by showing pictures of outcomes to help women to develop realistic expectations of the outcome of breast reconstruction. It has also been suggested that women should have the opportunity to handle silicone and saline implants to allow them to feel the weight and texture of implants¹⁴. Surgeons must also have adequate communication training to allow them to discuss this with patients in a way that ensures that patients feel that they have been involved in the decision-making process and are confident that they have made the decision that is right for them.

While guidelines state that immediate breast reconstruction should be discussed with all patients², there may be reasons for patients to have delayed breast reconstruction. Some patients may prefer to wait until their cancer

treatment is completed before considering breast reconstruction while for others, there might be medical reasons to delay breast reconstruction. For example, if radiotherapy is recommended, some patients are advised to delay breast reconstruction⁵.

Patients who have a family history of breast cancer may undergo genetic testing, the results of which may impact on the patient's surgery and reconstruction choices⁶. For most women, breast reconstruction will be a process rather than a single operation and they will need to return for additional operations⁶. The number of operations will depend on the patient and the type of reconstruction chosen and is something that each patient should discuss with their clinical team.

47.1%

Sheehan et al (2008) found that 47.1% of women experienced regret over their decision to have reconstructive surgery

Restriction of breast reconstruction services

In early 2017, Breast Cancer Now was becoming increasingly concerned that clinicians had reported that breast reconstruction surgeries were being restricted for non-clinical reasons. Reconstructive surgery may not be suitable for all patients, especially those who are overweight or obese, smokers or people with pre-existing conditions such as diabetes. These restrictions are clinically indicated and are not included in the restrictions that this report is addressing.

Non-clinical restrictions that patients are facing are taking one of three forms:

- **Limits on the number of surgeries a patient can have to complete breast reconstruction.**
- **Limits to the time in which breast reconstruction must be complete.**
- **Limits on the availability of balancing surgery to the unaffected breast for patients who choose breast reconstruction.**

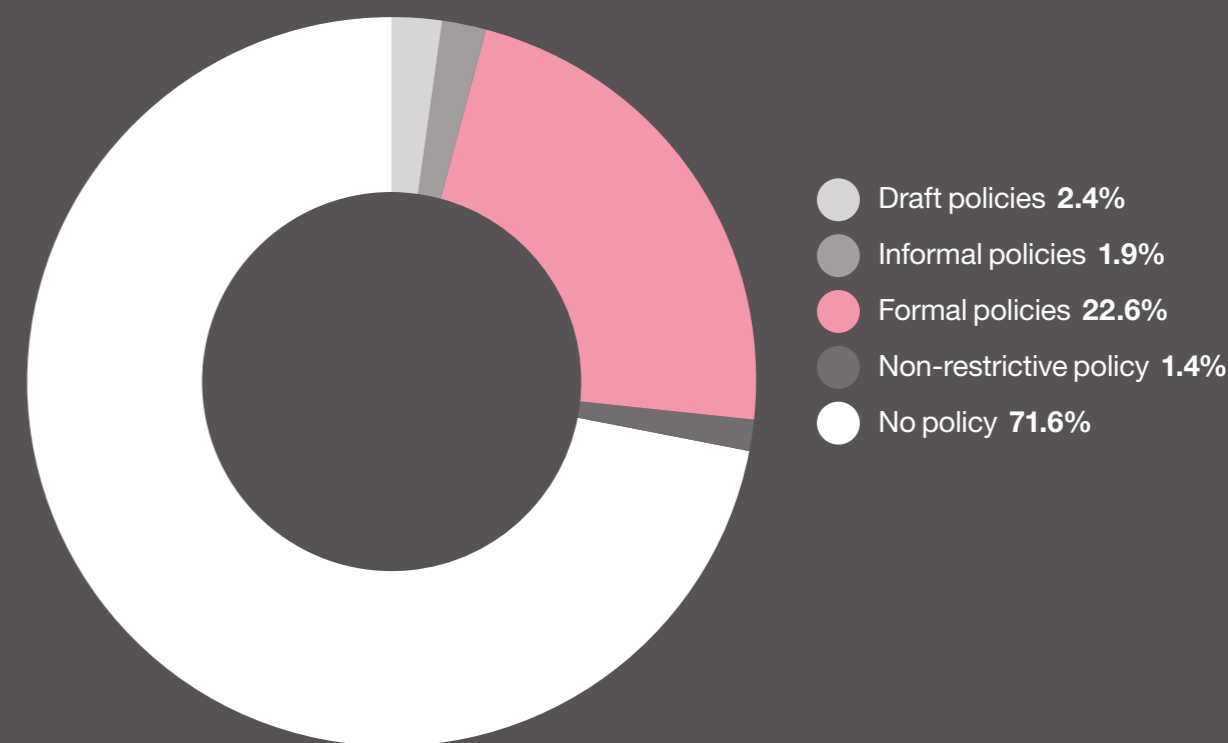
In March 2017 Breast Cancer Now requested details of breast reconstruction policies from all CCGs in England under the Freedom of Information Act. We received responses from all 208 CCGs and found that, whilst a minority (47) of CCGs currently have formal policies in place restricting access to breast reconstruction surgery, these restrictions varied widely and other CCGs are considering introducing further non-clinical restrictions.

Of the 47 CCGs with formal restrictions, 22 have been rated as either 'inadequate' or 'requires improvement' in NHS England's annual assessment¹⁵. These ratings are reached using NHS England's Improvement and Assessment Framework, and take into account the CCGs performance across a range of indicators as well as the financial management and leadership of the CCG¹⁶.

25% of the score for this assessment¹⁷ is based on a CCG's finances and while the reasons for introducing restrictions on breast reconstruction are unclear, we are aware that the NHS has been operating under immense financial pressure for the last decade. In his annual report from 2008/09, then NHS England Chief Executive David Nicholson stated that between 2011 and 2014, the NHS would need to make efficiency savings of £15-£20billion¹⁸. The first of the policies restricting breast reconstruction surgery were introduced in 2012 and may have been introduced as part of the drive to make efficiency savings.

In addition to those CCGs that have formal policies restricting breast reconstruction, a small number of CCGs (four) have informal policies that state that while there is no formal policy, the CCG would look to 'draw a line' when receiving requests for breast reconstruction more than five years after cancer treatment. Another small number of CCGs (three) have a formal policy on breast reconstruction that is not considered to be restrictive as it states that patients and surgeons should agree a satisfactory aesthetic endpoint for breast reconstruction surgery.

How many CCGs have formal policies in place restricting access to breast reconstruction surgery?



Formal restrictions to breast reconstruction

| CCG | Limits on number of surgeries | Time limits | Limits on balancing surgery |
|--------------------------------------|-------------------------------|-------------|-----------------------------|
| NHS Barking and Dagenham CCG | | | X |
| NHS Barnet CCG | | | X |
| NHS Basildon and Brentwood CCG | X | | |
| NHS Bedfordshire CCG | X | X | |
| NHS Birmingham CrossCity CCG | | | X |
| NHS Birmingham South Central CCG | | | X |
| NHS Camden CCG | | | X |
| NHS Cannock Chase CCG | | | X |
| NHS City and Hackney CCG | | | X |
| NHS Corby CCG | | | X |
| NHS Coventry and Rugby CCG | | X | |
| NHS Dorset CCG | | X | |
| NHS Dudley CCG | | | X |
| NHS East and North Hertfordshire CCG | X | X | |
| NHS East Staffordshire CCG | | | X |
| NHS Enfield CCG | | | X |
| NHS Gloucestershire CCG | X | X | |
| NHS Haringey CCG | | | X |
| NHS Havering CCG | | | X |
| NHS Herefordshire CCG | | X | |
| NHS Herts Valleys CCG | X | X | |
| NHS Islington CCG | | | X |
| NHS Luton CCG | X | X | |
| NHS Mid Essex CCG | X | | |
| NHS Newham CCG | | | X |
| NHS North Hampshire CCG | | X | |

| CCG | Limits on number of surgeries | Time limits | Limits on balancing surgery |
|--|-------------------------------|-------------|-----------------------------|
| NHS North Staffordshire CCG | | | X |
| NHS Redbridge CCG | | | X |
| NHS Redditch and Bromsgrove CCG | | X | |
| NHS Sandwell and West Birmingham | | | X |
| NHS Scarborough and Ryedale CCG | | X | |
| NHS Solihull CCG | | | X |
| NHS Somerset CCG | | | X |
| NHS South East Staffordshire and Seisdon Peninsula CCG | | | X |
| NHS South Warwickshire CCG | | X | |
| NHS South Worcestershire CCG | | X | |
| NHS Stafford and Surrounds CCG | | | X |
| NHS Stoke on Trent CCG | | | X |
| NHS Swindon CCG | | X | X |
| NHS Tower Hamlets CCG | | | X |
| NHS Walsall CCG | | | X |
| NHS Waltham Forest CCG | | | X |
| NHS Warwickshire North CCG | | X | |
| NHS West Essex CCG | | | X |
| NHS Wiltshire CCG | | X | |
| NHS Wolverhampton CCG | | | X |
| NHS Wyre Forest CCG | | X | |

In several cases, groups of CCGs have collaborated on policies regarding breast reconstruction. While in most cases this means that patients within a geographical area can expect to receive the same treatment, we came across one example of CCGs with conflicting policies. Across a group of 11 CCGs^a, we were referred to three different collaborative documents and three different individual policies on breast reconstruction, which sometimes had conflicting advice. One collaborative document with the names of all 11 CCGs stated that surgery to the unaffected breast will not be routinely funded while another collaborative document with the names of six of the CCGs stated that treatment to the unaffected breast will be funded as part of the original treatment plan but later requests for balancing surgery will not be routinely funded.

^a NHS Birmingham CrossCity CCG, NHS Birmingham South Central CCG, NHS Sandwell and West Birmingham CCG, NHS Solihull CCG, NHS Walsall CCG, NHS Wolverhampton CCG, NHS Cannock Chase CCG, NHS Stafford and Surrounds CCG, NHS South East Staffordshire and Seisdon Peninsula CCG, NHS East Staffordshire CCG and NHS Dudley CCG

Rebuilding my body Anna's story

I was diagnosed with primary breast cancer in September 2014, age 32. I had a lumpectomy and sentinel lymph node biopsy a month later, followed by chemotherapy and radiotherapy. I was assured I'd be offered reconstruction further down the line.

After my treatment finished, I saw a new surgeon and asked her for lipofilling. However, she thought the difference between my breasts wasn't significant enough to warrant doing anything. The difference wasn't minimal to me; half of my breast had been removed- the smaller one- along with my nipple.

I feel my mental health has been affected, and this should have been taken into consideration. My surgeon wasn't willing to consider what it meant to me, and didn't offer me any further support.

These policies are freely available online and we are concerned that patients looking for advice on their CCG's policies may find conflicting information. Perhaps more worrying is that surgeons in the same CCG may be working from different documents and therefore two patients in the same CCG may be offered different procedures.



What patients told us

A minority of patients responding to our survey reported that they had been told that there were restrictions on the availability of breast reconstruction or balancing surgery.

Of 453 women who answered the question about restrictions to surgery, 42 (9%) reported that they were told about non-clinical restrictions to breast reconstruction surgery.

26 of these were told that they couldn't have surgery to the unaffected breast, eight were told their reconstruction must be completed within a set time period, three were told they could only have a limited number of surgeries and five were told they could only have a limited number of surgeries and their reconstruction must be complete within a set time period.

'I was only told about the options that were open to me. I had no idea until later that I may have had other options. It was never explained why those were the only options I was offered. I had no experience to draw upon to ask for anything else or realise that my options had been restricted...

I feel that the limitations of how my clinical team offer information and the apparently restricted options they offer has had a long term impact on my physical and mental wellbeing. The complications, long term side effects, and lack of honest information from my clinical team stops me from pursuing reconstruction options.'

Breast cancer patient, 45-54, South East

Clinical guidelines

'I feel I can't draw a line under it all and move on and I also don't like to look at myself with things being unfinished.'

Breast cancer patient, 35-44, South East

'I feel that I was given information based on what my clinical team felt was a "need to know" basis. I was not given information unless I pushed for it, and I didn't know what questions I should be asking. When I did ask questions, I was never given full and honest answers, and this led me to doubt and mistrust any answers I was given as my treatment progressed.'

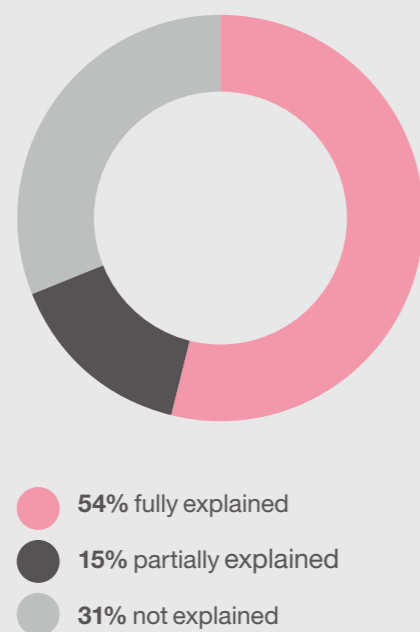
Breast cancer patient, 45-54, South East

Women were asked how being told about restrictions made them feel and whether they felt that this had an impact on their emotional and mental wellbeing.

The long term impact of these restrictions on the psychological wellbeing of breast cancer patients cannot be underestimated.

We also asked women if the reasons for the restrictions they were facing were explained to them. Of the 94 women who answered this question, 51 (54%) said the reasons were fully explained, 14 (15%) said they were partially explained and 29 (31%) said the reasons were not explained.

Are the reasons for the restrictions being faced explained?



The Association of Breast Surgery (ABS) has been aware of the restrictions being introduced by CCGs around England and is concerned about the lack of clinical evidence supporting the introduction of these restrictions and the resulting variation in practice.

To reduce the variation experienced by patients, the ABS, in partnership with Breast Cancer Now and the British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS), has produced guidelines for CCGs to support the planning of breast surgery¹⁹. These guidelines are intended to support commissioners to understand the complexities of breast surgery and to ensure that every effort is made to achieve the best outcome for patients using the best technique for each patient with as few procedures as possible, acknowledging that returning for multiple surgeries is not desirable for the patient or for the NHS.

The guidelines state that patients should be able to choose to return for breast reconstruction surgery at any point following their diagnosis and initial treatment. This is supported by existing

guidance with the NHS England Breast Cancer Clinical Expert Group highlighting this in their clinical advice for breast cancer:

*'Patients make decisions at very different speeds so delayed reconstruction or further operative procedures to optimise symmetry should be available without time restrictions.'*⁶

The guidelines advocate that a full range of symmetry and adjustment procedures should be available to patients, including balancing surgery on the unaffected breast. The guidelines state that in some circumstances mastectomy on an unaffected breast may be appropriate and referred to a previous ABS statement on this issue for further detail¹³.

The guidelines acknowledge that due to the relatively new techniques currently being used for breast reconstruction, there is no clinical consensus regarding the appropriate number of procedures that women will need to achieve a satisfactory result with their breast reconstruction.

As the evidence in this area develops, it may be possible to develop a clinical consensus in this area. In the meantime, the guidelines suggest for most patients, a satisfactory result should be possible within 2-3 procedures.

However, patients who do not achieve a satisfactory result in 2-3 surgeries or who experience complications that require further surgery should not be penalised and should still have access to corrective surgery.

This underlines the importance of clear communication between patients and surgeons throughout the breast surgery pathway and particularly in the planning stage. Patients need to understand clearly what is possible, and more importantly, what is not possible through breast reconstruction. Patients who go into breast reconstruction expecting to end up with breasts that are identical to their pre-cancer breasts are likely to be disappointed with the result.

Breast Cancer Now is supporting ongoing research to help women be clear about their expectations of breast reconstruction and to share those expectations with their surgeon.

Professor Diana Harcourt and colleagues at the University of the West of England have developed an intervention called PEGASUS (Patients' Expectations and Goals: Assisting Shared Understanding of Surgery). In this intervention women discuss their priorities for surgery with a specially trained nurse or psychologist, to help them discuss their expectations more easily with their surgeon. 180 women with breast cancer considering breast reconstruction at four hospitals will be asked to take part, half of whom will receive the PEGASUS intervention. At multiple points following surgery, all women will be asked to give a measure of their quality of life and satisfaction with the results of their surgery.

Professor Harcourt and colleagues hope to show that PEGASUS can help women who are considering breast reconstruction to be more satisfied with the decisions they make and the outcomes of their surgery. Ultimately this aims to ensure that women who are offered reconstructive surgery experience the best possible long-term quality of life. This study is expected to report in 2019.

Conclusion and recommendations

Breast reconstruction is an essential part of breast cancer treatment for many women and has a dramatic impact on the psychological wellbeing of breast cancer patients.

It is essential that breast reconstruction is not dismissed as a cosmetic procedure, as for many women, breasts form an essential part of body image, self-esteem and sexuality. Breast reconstruction offers the opportunity to regain this part of their identity after breast cancer treatment. It is therefore important that all patients have access to the full range of reconstruction surgery techniques as well as the highest quality breast reconstruction surgery to ensure the best possible outcome.

Effective communication between patients and healthcare professionals is also essential. Patients need to be able to be clear with their surgeons regarding their expectations of breast reconstruction and surgeons need to be honest and clear with their patients about what is possible, and often, what is not.

As breast cancer becomes a condition that women can live beyond, rather than die of, it is essential that women are given every opportunity to live well with their condition and for many women, breast reconstruction will help them to do that. Restricting the time in which a patient can have breast reconstruction and denying access to balancing surgery are backwards steps which may cause unnecessary

psychological distress for patients and their families. These restrictions are arbitrary, they cause unwarranted variation across England and they hamper the ability of patients to live well after a diagnosis of breast cancer. CCGs must take action to ensure that breast reconstruction surgery is planned with the needs of patients at their heart.

It is essential that breast reconstruction is not dismissed as a cosmetic procedure and that breast cancer patients have access to the breast reconstruction services they need

All CCGs should:

Ensure that patients who need breast reconstruction have access to the surgery they need, when they need it, by adopting the ABS guidelines and ensuring that unwarranted variation in breast reconstruction is avoided.

Provide all healthcare professionals involved in discussing breast reconstruction with patients with adequate training and support, to ensure that patients are aware of the full range of options available to them and have realistic expectations of breast reconstruction.

Provide patients and clinicians with shared decision making tools to help them to make decisions that are in the best interests of patients.

Ensure that all patients are offered appropriate and timely psychological support and counselling to help them to make a decision about breast reconstruction.

Show all patients photos of reconstructed breasts to help them to have realistic expectations of what breast reconstruction can achieve.

Report

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**We're Breast Cancer Now.
The UK's largest breast
cancer charity.**

**We believe that, by 2050,
everyone who develops
breast cancer will live –
and live well.**

But only if we all act now.

**breast cancer
now**

The logo for Breast Cancer Now features the words "breast cancer" in a smaller, lowercase, sans-serif font above the word "now" in a larger, bold, lowercase, sans-serif font. The letter "o" in "now" is replaced by a pink circle containing a white heart.

Breast Cancer Now is a charity registered in England and Wales (1160558), Scotland (SC045584) and the Isle of Man (1200).