

DELIVERING REAL CHOICE: THE FUTURE OF BREAST RECONSTRUCTION IN ENGLAND

**BREAST
CANCER
NOW** The research &
support charity

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FOREWORD



Baroness Delyth Morgan
Chief Executive, Breast
Cancer Now

Breast reconstruction, for those who choose it, is a core component of a patient's recovery, either from breast cancer or from risk-reducing surgery. It is not a superficial or aesthetic choice; it's reconstructing a woman's body and identity after they have been unravelled by treatment and surgery.

Women therefore must be able to access the right type of reconstruction for them, at the right time for them. But all too often, this access is being denied.

Some women aren't getting the support they need to make an informed decision about the right type of surgery for them. Others are aware of the options that are suitable for them but are experiencing difficulties in accessing a type of reconstruction called free flap. As a result, some women may be opting for surgeries they wouldn't otherwise have chosen, while others are having to put up with significant delays, made even worse by the COVID-19 pandemic.

In some local areas, there are additional restrictions that limit the timeframe for reconstruction, or the number of surgeries a woman can have. This creates a postcode lottery for patients, and additional pressure for those who see their window of opportunity closing.

This experience of being stuck in limbo can cause anxiety, feed a loss of self-esteem and identity, and hinder the ability for women to rebuild their lives, knowing their treatment is incomplete.

As the NHS seeks to recover from the backlog of surgery that built up during the pandemic, we must address these failings and put breast reconstruction on a much sounder footing. This means delivering informed and equitable access to breast reconstruction services for all those who choose them, both now and in the future.

The following report builds on robust research to outline how this can be achieved.

A handwritten signature in black ink that reads "Delyth".

Baroness Delyth Morgan
Chief Executive, Breast Cancer Now

SUMMARY OF RECOMMENDATIONS

Women must be given information about the different types of reconstruction and supported to make the decision that is right for them.

As part of the update and delivery of the revised NHS Long Term Plan, NHS England should require Cancer Alliances to:

- Further support the implementation and delivery of shared decision-making tools for breast reconstruction, such as PEGASUS.
- Promote patient information on breast reconstruction, such as Breast Cancer Now's resources.¹
- Require Patient Reported Outcome Measures (PROMs) to be collected, for example via the BreastQ questionnaire for all reconstruction surgery.²

Services must be structured in a way that enables patients to access the type of reconstruction that is right for them.

- NHS England should require Integrated Care Systems (ICSSs) and Cancer Alliances to ensure that arrangements are in place for patients to access all types of breast reconstruction, through the 2023-2024 NHS Priorities and Operational Planning Guidance and the upcoming Cancer Plan.
- This should include oncoplastic multi-disciplinary teams (MDTs), which should include plastic surgeons, or parallel clinics, and clear referral pathways, for example through hub and spoke models. Where necessary, these arrangements will need to work across Cancer Alliances and ICSSs.

Capacity to perform free flap breast reconstruction must be increased.

NHS England should work in partnership with Cancer Alliances and Integrated Care Systems to:

- Increase the number of trusts that provide free flap reconstruction
- Ensure that surgeons have the necessary theatre space, theatre and ward teams to provide this surgery.
- As part of the upcoming 15-Year Workforce Plan, NHS England should undertake regular modelling of the breast surgery workforce, including plastic and breast surgeons, to identify the numbers needed to meet the demand for breast reconstruction, both now and in the longer term. And the Government must provide the multi-year funding necessary to ensure that this workforce is recruited, trained, and retained.

The payment for breast reconstruction must reflect the true cost over time.

- NHS England's upcoming new NHS payment scheme, including its rules and pricing, should reflect the full, long-term cost of breast reconstruction.

All local restrictions on breast reconstruction must be removed

- NHS England should direct ICSSs to remove any local restrictions on breast reconstruction in their areas, including time limits, and limits on the number or type of procedures.

The backlog and long delays facing those awaiting breast reconstruction or risk-reducing surgery must be addressed.

NHS England should:

- Incorporate breast reconstruction within the Referral to Treatment target, so the timescales for recovery set out in NHS Elective Recovery Plan apply to it, and long waits are eliminated moving forward.
- Work with Breast Cancer Now, the Association of Breast Surgery (ABS) and the British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS) to establish a plan of recovery for breast reconstruction services.
- Support Cancer Alliances and ICSSs to introduce or continue to deliver initiatives to address the backlog, such as dedicated elective surgical hubs, continued use of the independent sector, and reconstruction rotas.

Consistent data must be collected on the number of patients waiting for breast reconstruction and risk-reducing surgery, and how long they have been waiting, both locally and nationally.

- NHS England should also include breast reconstruction in the single integrated audit programme for breast cancer.

ABOUT BREAST CANCER NOW

We're Breast Cancer Now, the research and support charity. We're the place to turn to for anything and everything to do with breast cancer.

The brightest minds in breast cancer research are here. Making life-saving research happen in labs across the UK and Ireland. Support services, trustworthy breast cancer information and specialist nurses are here. Ready to support you, whenever you need it. Dedicated campaigners are here. Fighting for the best possible treatment, services and care, for anyone affected by breast cancer.

Why? Because we believe that **by 2050, everyone diagnosed with breast cancer will live** – and be supported to live well. But to create that future, we need to act now.

WHATEVER YOU'RE GOING THROUGH.
WHOEVER YOU ARE.
WE'RE HERE.

BREAST
CANCER
NOW The research & support charity

ACKNOWLEDGEMENTS

We'd like to thank all the people who participated in our survey, along with the women whose stories we have referenced throughout this report.

Your experiences and insights have shaped and deepened our understanding and brought home the importance of informed access to breast reconstruction at the right time and in the right place. Thank you.

We'd also like to thank the leadership and members of the ABS and BAPRAS who participated in our reconstruction summit and subsequent engagement, particularly Professor Chris Holcombe and Ms Ruth Waters. Your clinical expertise and knowledge have been vital in developing this report.

Thank you also to Tracey Irvine, Senior Clinical Advisor for the Getting it Right First Time (GIRFT) work on breast surgery, which highlights the issues with access to breast reconstruction.

Finally, we're grateful to the healthcare professionals who we've spoken to and engaged with throughout the project. Your perspectives have been invaluable to understand the regional variation of breast reconstruction services across England.

INTRODUCTION

For those who choose it, breast reconstruction is an important part of recovery from breast cancer, or risk-reducing surgery. It's not a superficial procedure, it is rebuilding their body and is integral to regaining their sense of self and improving their wellbeing.

Through our survey, we found that of 1,246 people who either underwent reconstruction surgery or were waiting for it more than 9 in 10 (92%) felt reconstruction was an important part of their recovery.

Breast reconstruction is also important to those who either had or were waiting for risk-reducing surgery.

Of those from our survey with experience of risk-reducing surgery, 75% had breast reconstruction.

Despite this being such a high priority for the women involved, we know, from existing research, our own survey, the freedom of information (FOI) requests we put into hospital trusts, and our reconstruction summit with healthcare professionals, that not everyone in England has equal access to breast reconstruction services, or even to information about their options.

In some areas, limits are still being placed on the amount of time a woman has to request a reconstruction, or the number of operations she can have. Plus, reconstruction services are still in various states of recovery after being disrupted by the COVID-19 pandemic, with many still struggling with long delays.

Right now, some women are not being offered reconstruction at all, while others are being given only limited options and very little say in how their care is being planned and delivered.

While there are pockets of best practice in delivering breast reconstruction, these must now be replicated, wherever necessary or appropriate. And further action must be taken to ensure that all women who want reconstruction can make an informed choice about the type of surgery that is right for them and then access that surgery when they want it, wherever they happen to live.

This report includes pragmatic recommendations for how these outcomes can be achieved, alongside the experiences of women who illustrate the importance of patient choice and good communication at every stage of breast surgery and reconstruction.



92%

FELT RECONSTRUCTION WAS AN **IMPORTANT PART OF THEIR RECOVERY**

BREAST CANCER NOW AND BREAST RECONSTRUCTION

We have long promoted the importance of body image after breast cancer. One of the ways we have done this is by advocating for access to different types of breast reconstruction, as well as symmetrisation or balancing surgery in previous reports,³ including My body, myself and Rebuilding my body,⁴ which also highlighted local variations in the availability of reconstruction services. We have also commissioned research and hosted events which have explored with women how breast cancer has impacted on their body image.⁵

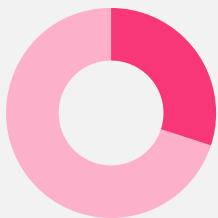
We have worked with ABS and BAPRAS to develop commissioning guidance for reconstruction⁶ and the GIRFT review of breast surgery across England, which identified best practice and areas of improvement for breast reconstruction services.⁷

The majority of women choose not to have breast reconstruction after a mastectomy for breast cancer. They may choose to use a breast prostheses or to live flat. These are very personal decisions.

BREAST RECONSTRUCTION KEY STATISTICS



30% HAVE A MASTECTOMY



ONLY 40 OUT OF 130 (30%) TRUSTS PROVIDE FREE FLAP RECONSTRUCTION



34% DECREASE IN BREAST RECONSTRUCTION ACTIVITY IN 2021-2022 COMPARED TO 2018-2019

Around 30% of women diagnosed with breast cancer have a mastectomy.⁸

When women have their reconstruction varies. Nationally 27% of women who have a single mastectomy for cancer have an immediate reconstruction.⁹ Our survey found that, of those who opted for reconstruction, 64% had immediate reconstruction and 35% either had or were awaiting delayed reconstruction.

There is also variation in the type of breast reconstruction. There were around 2,000 free flap reconstructions conducted each year between 2015 and 2018, of which 650-700 were immediate and the rest were delayed.¹⁰

Yet not all hospitals provide free flap reconstruction. Of around 130 trusts in England with breast units, only around 40 trusts provide free flap reconstruction.¹¹

The pandemic has severely impacted breast reconstruction. in 2020-2021 there was a 64% decrease in breast reconstruction activity compared to 2018/19.¹²

Breast reconstruction surgeries have not yet recovered to pre-pandemic levels, in 2021-2022 there was a 34% decrease in breast reconstruction activity compared to 2018-2019.¹³

We know from the experiences of those who have had or are waiting for breast reconstruction this has a huge impact.

PATIENT INFORMATION AND JOINT DECISION MAKING

Everyone who is considering breast reconstruction, whether as part of, or after surgery for breast cancer, or to reduce their risk of the disease, must be able to make an informed decision about their surgery. This means understanding all of the options available, which will be suitable for them, and being supported to make the right choice by a specialist healthcare professional.

This type of shared decision making is central to ‘personalised care’, which recognises the need for people to have choice as well as control over the way that their care is planned and delivered, based on what matters to them.¹⁴

Our survey found that more than 7 in 10 women (73%) who received breast surgery or were waiting for it, felt breast reconstruction was extremely important to be aware of the different options available.

Having this support is especially important in the area of breast reconstruction, given all of the complex decisions involved, especially as these decisions often need to be made during cancer treatment.

Our survey found **7 in 10 (71%)** respondents were offered breast reconstruction.

Only around **6 in 10** of those who had or were waiting for surgery for breast cancer (65%) ‘definitely’ felt involved in decision making as to whether or not to have reconstruction surgery.

And of those who had or were waiting for breast reconstruction, only around half (53%) ‘definitely’ felt they were offered the full range of reconstruction options, while around 1 in 10 (12%) felt they were not offered all the options.

Almost **1 in 5 (19%)** of the women who had or were awaiting breast reconstruction felt they were unable to access support as part of decision making around their breast reconstruction.



FELT IT WAS IMPORTANT TO BE AWARE OF THE DIFFERENT OPTIONS AVAILABLE

For example, women may need to decide whether to delay reconstructive surgery or to have an immediate reconstruction, and whether to have an implant or to use tissue from other parts of the body, known as ‘free flap’ surgery.

To ensure they make an informed decision, women must know how different types of reconstruction may look and feel, how long it might take to recover, and how many operations may be involved, as well as potential complications. They should also be made aware of the evidence on the short and long-term outcomes of each type of reconstruction, including patient satisfaction with them.¹⁵ Plus, women may have preferences to factor in around when and where the surgery can be arranged, and what’s available closest to home. And they must be given this information in the way that best suits them.

It’s all of these things together that determine what is right for them.

Barriers to informed choices and shared decisions

Despite the complex picture and the recognised importance of personalised care, not all patients are being given the opportunity to participate in decisions about their own bodies – or even offered reconstruction at all.

Our survey found when people are uninformed or unable to participate in decisions about their own care, it is not only damaging to them, but also out of line with clinical guidance.

NICE guidelines recommend that healthcare professionals discuss with their patients different breast reconstruction surgery options and what they involve, including the benefits and risks, as well as the timing of breast reconstruction surgery, offering both immediate and delayed reconstruction, regardless of what is available locally.¹⁶

The NHS Constitution for England also commits to enabling patients to participate in their own healthcare decisions and to support them in making an informed choice.¹⁷ Indeed, one of the Women's Health Strategy for England ambitions is to embed personalised care and shared decision making into all areas of women's health.¹⁸

Despite these ambitions, our survey reveals that the commitment made in the NHS Long Term Plan – that by 2021, where appropriate, every person diagnosed with cancer will have access to personalised care – is not being met.¹⁹

Why personal decisions need professional support

While options relating to breast reconstruction can depend on a patient's circumstances, especially in regard to previous treatment, or the presence of other diseases or conditions (known as co-morbidities), healthcare professionals should offer *all* suitable options so that individuals are able to participate in decisions about their own care.

However, some healthcare professionals may only offer certain options to patients, such as implant based surgery. This may be because free flap reconstruction is not available locally, or they may be concerned about whether patients will be able to access immediate free flap surgery within the cancer waiting time targets. These are 62 days from GP referral, or 31 days from a decision to treat, either as a first or subsequent treatment.²⁰ Also, they may not have the knowledge and skills necessary to approach shared decision making.

It's vital then that healthcare professionals, including surgeons, are supported in this area. Particularly as there is evidence to suggest that people with breast cancer can feel a strong alliance with their surgeon after their first meeting. This highlights the important role healthcare professionals play in supporting decision making.²¹

THE PEGASUS TOOL

The PEGASUS tool was developed by psychologists at the Centre for Appearance Research, University of the West of England at Bristol, and part funded by Breast Cancer Now to assist those considering breast reconstruction.

Patients work with a trained PEGASUS coach to discuss their expectations and goals specific to reconstructive surgery, which are then used to guide their consultation with a reconstruction surgeon.

In a trial, women who used the PEGASUS tool reported less regret about their decision in the short term as well as an improvement in quality of life in the longer term, when compared with patients who received standard care without PEGASUS.²⁴

'IN THE END, I WAS SO UPSET WITH THE WHOLE THING, I TRANSFERRED TO ANOTHER TRUST WHERE MY EXPERIENCE WAS FANTASTIC.'



HELEN'S STORY 'YOU CAN'T HAVE THAT DONE HERE'

Helen wanted to have DIEP flap reconstruction as it suited her personal and clinical circumstances best. She never thought she'd have to self-refer to another trust to access it.

Helen was keen to understand her options: 'I knew I had to have surgery but for my own peace of mind, needed to do my own research, before discussing the options with the consultant' she says. 'I just thought... the best outcome from this would be if they could do my reconstruction from my stomach.' But when she spoke to her doctor about wanting to have DIEP and TUG Flap surgery, she was shocked by his reaction.

'I spoke to the doctor... and he said "If you want that done - you'll have to go abroad, I can't do that." My research and my knowledge of the procedure options were also dismissed. I was there with my partner. We both were aghast at what he'd said.'

'In the end, I was so upset with the whole thing, I transferred to another trust where my experience was fantastic. It put everything into perspective. It made me realise I had been very badly treated.'

This wasn't an easy process. Helen did all the research and all the

legwork herself to support the referral to another trust: 'I found the surgeons I needed. I was constantly ringing the secretaries to get myself slotted in and chasing letters all of the time...'

Helen felt she was extremely well cared for despite some complications from her reconstruction, particularly by the staff who treated her. She also received good follow-up support following surgery.

'It felt selfish that I wanted my body image back'

'I thought after, when I looked back at myself, it felt selfish that I wanted my body image back,' says Helen.

'But it becomes more important that you have the right surgery for the reconstruction.'

Fortunately, Helen was able to find the right solution for her. But it was an uphill struggle.

To provide appropriate support, healthcare professionals must be equipped with the tools they need to work effectively with patients. For example the Patient Expectations and Goals: Assisting Shared Decision Understanding of Surgery (PEGASUS) tool – is designed to help women and their clinicians clarify expectations around reconstructive surgery, evaluate the options, and jointly decide on the best approach to take.²²

Healthcare professionals can also be supported to deliver better shared decision making, through training to develop their communication skills and the provision of good quality information, such as our reconstruction resources.²³

It's also vital that women's experiences of breast reconstruction are collected and shared via PROMs; something that does not happen routinely for this type of surgery. This enables healthcare professionals and patients to understand the impact of the treatment and care provided to inform shared decision making.

However, even where all suitable options for breast reconstruction are offered, and shared decision making is used, the other issues at play may impact the choices that patients make. For example, they may be put off free flap surgery because it is not available locally, or because of how long they may have to wait for it. If patients are to be offered real choice, then alongside shared decision making, these issues must be addressed. This is considered in the next section of this report.

RECOMMENDATION:

Women must be given information about the different types of reconstruction and supported to make the decision that is right for them.

As part of the update and delivery of the revised NHS Long Term Plan, NHS England should require Cancer Alliances to:

- Further support the implementation and delivery of shared decision-making tools for breast reconstruction, such as PEGASUS.
- Promote patient information on breast reconstruction, such as Breast Cancer Now's resources.²⁵
- Require PROMS to be collected, for example via the BreastQ questionnaire for all reconstruction surgery.²⁶

ACCESS TO RECONSTRUCTION AND TYPES OF SURGERY

Women must be able to access the right type of reconstruction for them, whether they want the surgery straightaway or choose to delay it.

However, the Getting It Right First Time (GIRFT) review of breast surgery across England, found huge variation in both the timing and type of breast reconstruction being undertaken, that is unlikely to result solely from patient choice. For example:

- **When it comes to timing,** around 1 in 4 women (27%) who have a single mastectomy due to breast cancer have an immediate reconstruction.²⁷ However, this varies hugely between trusts - from as few as 3% to as many as 75%.²⁸
- **When it comes to type,** more than 1 in 5 reconstructions use free flap surgery. However, this number also varies from trust to trust.²⁹

Variations in the type of reconstruction used can be due to what is available locally. In the estimated 40 trusts that have a free flap service,³⁰ approaching half (45%) of immediate reconstructions are undertaken using this method. Whereas in trusts that do not have a free flap service, less than a third (30%) of immediate reconstructions are free flap.

According to BAPRAS,³¹ this limited capacity for free flap surgery had resulted in waiting times for reconstruction of up to two years

in some trusts – and that was before COVID-19 hit. The problem has not gone away, as you can see in the next section of this report, which explores the impact of the pandemic in more detail.

Unsurprisingly, our survey also found that not everyone who responded was able to access the right reconstruction for them at the right time.

Our survey found that of those respondents who had or were waiting for breast reconstruction, 9% felt they weren't able to access their preferred type of reconstruction, and over 1 in 10 (15%) felt they were unable to access reconstruction at the right time. Additionally, 15% felt they were not able to access symmetrisation or balancing surgery.

What all these figures suggest is that many women who want an immediate reconstruction may be compromising and choosing implant surgery or delaying their reconstruction, to ensure they can have free flap surgery. These choices may not be right for them, and they may feel dissatisfied with the results in the longer term.

There are a number of interrelated factors that can affect access to surgery.

These include whether a trust has a free flap service, the way services are structured, the reconstruction workforce, and the way surgery is paid for, as well as additional restrictions that may be applied locally.



1/2

LESS THAN HALF THE TRUSTS INVITED PLASTIC SURGEONS TO PROVIDE RECONSTRUCTION EXPERTISE

Less than half the trusts visited by the GIRFT breast surgery team had oncoplastic MDTs. And only half of them had invited a plastic surgeon to join it to provide expertise in free flap reconstruction.⁴³

78

ADDITIONAL PLASTIC SURGEONS ARE REQUIRED

Service structures that minimise choice

While most trusts have breast surgeons, trained in breast cancer surgery and some types of breast reconstruction (known as oncoplastic surgeons), free flap surgery typically requires the skills of a plastic surgeon as oncoplastic surgeons are not trained in the micro-surgical techniques required for this type of reconstruction.

However, not every trust that undertakes breast surgery also delivers plastic surgery, with only an estimated 40 out of around 130 trusts that have breast units currently having a free flap service.³² Outside of these areas, patients will often need to be referred to another trust to access this type of reconstruction, and their referral may not be accepted due to waiting lists or costs.

In addition, trusts may not have a MDT which specifically looks at breast reconstruction (also known as an 'oncoplastic MDT'). This means the opportunity for healthcare professionals to explore different reconstruction options for their patients may be being missed.

In order to provide a service which supports women to access all types of reconstruction in a timely manner, we need to improve collaboration between breast and plastic surgeons, and trusts and ensure that plastic surgery expertise is provided for each trust. This could include joint or parallel clinics involving both breast and plastic surgeons, or oncoplastic MDTs involving plastic surgeons from outside as well as inside the trust.³³

HUB AND SPOKE MODEL

Queen Victoria Hospital (QVH) in East Grinstead is a specialist NHS hospital which provides breast reconstructive surgery through a hub and spoke model. They work with 19 hospitals across Kent and Medway Cancer Alliance and Surrey and Sussex Cancer Alliance. The hospital provides a range of different types of reconstruction, including options for free flap reconstruction such as deep inferior epigastric perforator (DIEP) flap, transverse upper gracilis (TUG) or L-shaped upper gracilis (LUG) flap. They also do more complex reconstructions such as stacked and bipedicled, and bilateral breast reconstructions.

Patients in the region are able to access free flap breast reconstruction which is not provided in their local hospital by having their breast reconstruction at QVH. This is delivered by QVH's nine plastic surgery consultants specialising in breast reconstruction who hold clinics at both QVH and in 'spoke' clinics in various hospitals across Kent, Surrey, and Sussex. These clinics are either delivered in parallel with gene carrier or oncology clinics, or provided as separate plastic surgery clinics. This means that patients can have consultations at their local

hospital, minimising their travel to QVH. The QVH consultant plastic surgeons also participate in a joint oncoplastic MDT with other hospitals from the catchment area such as Royal Surrey County Hospital & University Hospitals Sussex in Worthing and Chichester. The QVH provides patients with information on the different surgeries and hosts a reconstructive support group through the charity Restore in the format of 'show and tell' information events. These events enable patients to find out further information, view reconstructive results and decide on the surgery which is right for them.

Over half of the reconstructions undertaken at QVH are immediate breast reconstructions, with the other half being delayed reconstructions and risk-reducing surgery. Patients are able to return to QVH for follow up clinics or see their surgeon in the 'spoke' clinics. If they have any problems following their surgery, the hospital's breast reconstruction clinical nurse specialists support and triage patients over the phone/virtually to avoid additional travel.

Regions could also create a hub and spoke model, where ‘spoke’ trusts could refer their patients to a regional ‘hub’ for free flap reconstruction.³⁴ This would support the development of a well networked referral pathway that enables patients to access the support they need more easily.

RECOMMENDATION:

Services must be structured in a way that enables patients to access the type of reconstruction that is right for them.

- NHS England should require ICSs and Cancer Alliances to ensure that arrangements are in place for patients to access all types of breast reconstruction, through the 2023-2024 NHS Priorities and Operational Planning Guidance and the upcoming Cancer Plan.
- This should include oncoplastic MDTs, which should include plastic surgeons, or parallel clinics, and clear referral pathways, for example through hub and spoke models. Where necessary, these arrangements will need to work across Cancer Alliances and ICSs.

A lack of capacity for free flap reconstruction

As set out earlier in this section of the report, it is estimated that only around 40 trusts out of the 130 trusts with breast units provide free flap reconstruction. Some women may not wish to travel to access free flap reconstruction. Others may be put off by long waiting lists in trusts that do provide this surgery.

Furthermore, in addition to the shortfall in staff across the broader breast cancer workforce, there is specifically an insufficient number of plastic surgeons to deliver the amount of free flap reconstructions needed.

A recent UK-wide study estimates that an additional 78 plastic surgeons are required just to meet current demand for free flap breast reconstruction.³⁵

To compound this shortfall, the training for new surgeons was disrupted during the pandemic,³⁶ when surgeries were postponed, and many surgical and plastic trainees were redeployed to other parts of the NHS.

RECOMMENDATION:

Capacity to perform free flap breast reconstruction must be increased.

NHS England should work in partnership with Cancer Alliances and Integrated Care Systems to:

- Increase the number of trusts that provide free flap reconstruction.
- Ensure that surgeons have the necessary theatre space, theatre and ward teams to provide this surgery.
- As part of the upcoming 15 Year Workforce Plan, NHS England should undertake regular modelling of the breast surgery workforce, including plastic and breast surgeons, to identify the numbers needed to meet the demand for breast reconstruction, both now and in the longer term. And the Government must provide the multi-year funding necessary to ensure that this workforce is recruited, trained, and retained.

Payment systems to reflect the true cost of surgery

The Health and Care Act 2022 requires NHS England to publish a new payment scheme which will replace the current national tariff.³⁷ The new scheme will provide single, joined-up pricing structures covering entire care pathways. This is vital for breast reconstruction, as patients may require further treatment. For example, the long-term cost for free flap and implant reconstruction is similar, £10,779 for free flap and £10,180 for implant-based reconstruction due to the greater number of follow up procedures required for implant reconstruction. But the initial cost for implant-based reconstruction is £3,824 and for free flap is £6,458.³⁸ NHS England must take this opportunity to ensure the costs of the reconstruction pathway are properly reflected.

RECOMMENDATION:

The payment for breast reconstruction must reflect the true cost over time.

NHS England's upcoming new NHS payment scheme, including its rules and pricing, should reflect the full, long-term cost of breast reconstruction.



ALISON'S STORY 'IT WENT ON AND ON...'

After breast cancer surgery and radiotherapy, Alison felt that a delayed DIEP flap reconstruction would be best for her. But she had no idea just how long she would have to wait.

'I literally thought I would be having my reconstruction within 12 months', says Alison: 'That was the bit that I found very hard to mentally process... the fact that it went on and on.'

'I UNDERSTOOD THAT I DIDN'T NEED THE SURGERY, BUT IT WAS STILL QUITE HARD TO GET ON WITH YOUR LIFE IN BETWEEN.'

'I feel like there wasn't really anyone to turn to because I'd finished my treatment. I think a lot of people say the same: you're supported amazingly through treatment, but of course that comes to an end... and you kind of feel a bit "left".'

'I understood that I didn't need the surgery, but it was still quite hard to get on with your life in between.'

In the end, it took almost three and a half years for Alison to receive her reconstruction. And she had to change plastic surgeons too, as the one she should have had was just too busy.

Fortunately, Alison feels her surgeon turned out to be 'fantastic'.

'It really did give me 100% of my confidence back. Probably more so.'

Restricting access to reconstruction locally

Our 2018 report *Rebuilding my body* highlighted that some Clinical Commissioning Groups (CCGs) across England were placing restrictions on breast reconstruction.³⁹ Our 2022 FOI request and further analysis found that some of these restrictions are still in place.

We found there are 16 trusts that are currently operating under restrictions, with 7 having a combination of restrictions with limits on both the time and number of procedures.

This was also highlighted in our survey, which found that almost 1 in 5 respondents (19%) felt they had encountered such restrictions.

Main types of restrictions on breast reconstruction

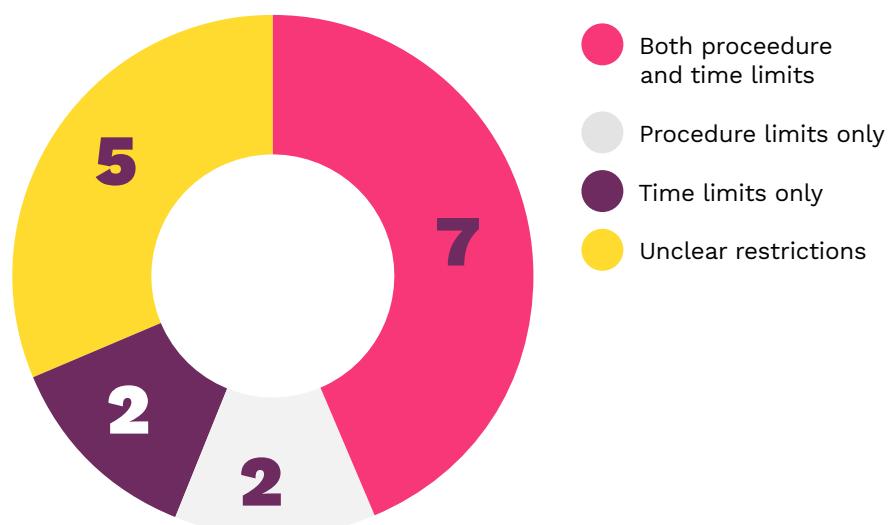
Time - a deadline on the time available for women to access reconstruction after their breast cancer or risk-reducing surgery. This has a negative impact on women who would rather delay their surgery and who may feel pressured to have surgery before they are ready

- Our FOI data showed most time limits were for five years following either cancer treatment or following initial reconstruction surgery

Number – limits on the number of reconstruction surgeries a patient can access. While every effort should be made to ensure the best outcome for every patient, with as few procedures as possible and surgeons aiming to minimise the need for adjustments,⁴⁰ patients should not be penalised if further surgery is required. Breast reconstruction is a complex process and multiple operations may be needed, either because of complications or to achieve a satisfactory result

- Our FOI data shows that most restrictions were for up to 3 procedures

Number of hospitals/trusts with local restrictions



Type – limits on symmetrisation or balancing procedures if the unaffected breast does not match the size and shape of the reconstructed breast, meaning further surgery is needed to give a more symmetrical result. Without routine funding for these procedures, some women will not be able to access this surgery and will therefore be dissatisfied with the final result of their reconstruction. This may in turn have an impact on their body image and self-esteem

Charities, healthcare professionals and NHS England have all sought to encourage the removal of local restrictions.

For example, the Women's Health Strategy for England⁴¹ stipulated no local time limits should be applied to reconstructive surgery. However, this does not cover

either the number of procedures or access to balancing surgery for the unaffected breast.

ABS and BAPRAS' Guidance on Commissioning of Oncoplastic Breast Surgery⁴² also called for the removal of local restrictions to ensure that patients are not penalised if they require additional procedures, or need access to symmetrisation or balancing surgeries.

As ICSs have recently taken over from CCGs for commissioning breast surgery, now is an opportune time to remove these restrictions and prevent them from being applied across the whole of an ICS – especially as these cover a larger area than CCGs.

RECOMMENDATION:

All local restrictions on breast reconstruction must be removed.

NHS England should direct ICSs to remove any local restrictions on breast reconstruction in their areas, including time limits, and limits on the number or type of procedures.

IMPACT OF THE PANDEMIC ON RECONSTRUCTION AND RISK-REDUCING SERVICES

As highlighted in an earlier section of this report, BAPRAS has said that the limited capacity for free flap reconstruction had resulted in waiting times of up to two years for reconstruction in some trusts before the COVID-19 pandemic.

As outlined in our Press Play report COVID-19 is the biggest crisis that breast cancer has faced in decades.⁴⁴ While many patients' treatment continued unchanged, other patients saw delays and cancellations, including for breast reconstruction. The approach to recovering services has varied between areas, with reconstruction services not being prioritised.

Pausing and restarting services

During the first wave of the pandemic, NHS England issued guidance for trusts to continue the delivery of vital cancer services, including surgery. However, other services, including breast reconstruction and risk-reducing surgery, were paused.^{45 46 47}

ABS and BAPRAS advised that breast reconstruction should be restarted in June 2020 beginning with immediate reconstruction.

Of the 59 trusts who responded to the question in our FOI request about when immediate breast reconstruction was restarted, the median time was July 2020. The latest restart time was May 2022. Of the 53 trusts who responded to the question about when delayed reconstruction was restarted, the median time was October 2020. The latest restart time was June 2022. In addition, one trust told us they had not yet restarted breast reconstruction at all.

Deprioritising reconstructive surgery

As breast reconstruction surgery began to start up again, the Federation of Surgical Specialty Associations published a prioritisation framework with guidance for trusts on which surgeries they should prioritise.

Risk-reducing surgery was categorised as priority 3 (out of 4), and delayed breast reconstruction priority 4.⁴⁸ This means that these surgeries have not been prioritised for available theatre space – a situation made worse by staff shortages caused by COVID-related absence.

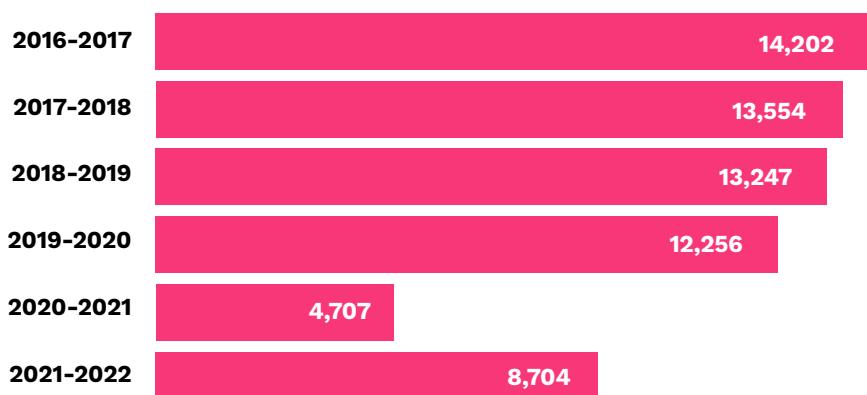
Of the 20 trusts that responded to the question in our FOI request about the capacity at which immediate breast reconstruction services were currently operating, compared to before the pandemic, the average capacity was 85%.

However, of the 18 trusts that responded in relation to delayed breast reconstruction, the average capacity was much lower, at only 42%.

| | Immediate reconstruction | Delayed reconstruction |
|-------------------------|--------------------------|------------------------|
| Earliest restart | April 2020 | June 2020 |
| Median restart | July 2020 | October 2020 |
| Latest restart* | May 2022 | June 2022 |

*Excludes one trust that have not yet restarted

Hospital episode statistics - Breast reconstruction activity



1,500

WOMEN WILL HAVE
MISSSED OUT ON
RECONSTRUCTION

Between March and July 2020, when breast reconstruction services were paused during the first wave of the pandemic, we estimated that around 1,500 women missed out on reconstruction, including 1,000 who would have had immediate reconstruction and 500 who would have had delayed reconstruction.⁶⁷

The impact on patients

The impact of this pause and restart, with most breast reconstruction services still not operating at full capacity, is an inevitable drop in the number of breast reconstructions being undertaken - and even longer waiting times.

Hospital episode statistics (HES) provide data on all admissions, outpatient appointments and A&E attendances at NHS hospitals. For breast reconstruction, this shows that there was a drop in activity of 64% in 2020-2021 compared to 2018-2019. Although activity increased in 2021-2022, there was still a 34% decrease compared to 2018-2019.⁴⁹

This evidences the need for further action to be taken to support the recovery of breast reconstruction to pre-pandemic levels.

Of the 32 trusts that provided a usable response to the question in our FOI request on current waiting times for

delayed reconstruction, the average wait for implant-based reconstruction was more than six months (36.5 weeks). The average wait for free flap reconstruction was just under a year (50.5 weeks). However, according to our survey, 40% of those waiting for breast reconstruction during the pandemic had waited two years or more (104+ weeks).

Naturally, this has had a huge impact on patients waiting for delayed breast reconstruction surgery.

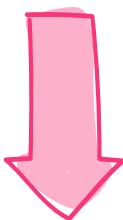
In our survey, just over half (51%) of respondents waiting for breast reconstruction surgery felt the pandemic had a significant impact on their wait and experience. Specifically, half (50%) felt unhappy with their body image, and more than 2 in 5 (42%) experienced a negative impact on their emotional wellbeing.

Those who were waiting for or underwent breast reconstruction during the pandemic were also more likely to have negative feelings about the outcome when they eventually had surgery. For example, under half (47%) of those who had or were waiting for reconstruction during the pandemic felt happy with the outcome, compared with almost two thirds (65%) of those who had reconstruction prior to the pandemic.

Of those who had or were waiting for risk-reducing surgery, 2 in 5 (41%) felt the pandemic had a significant impact on their wait for and experience of this surgery. And anecdotally, we have heard of some

instances where people who were identified as being at increased risk of breast cancer went on to develop the disease during their wait.

The impact of delays and backlogs highlights the importance of taking action in both areas to ensure that women can complete their recovery, or reduce their risk of developing breast cancer.⁵⁰



64%

DROP IN BREAST RECONSTRUCTION ACTIVITY IN 2020-2021 COMPARED TO 2018-2019⁶⁶

Pandemic recovery and continued deprioritisation

Work is already underway to recover and restore NHS services, however this has not fully met the needs of patients waiting for breast reconstruction.

For example, The Elective Recovery Plan sets out a number of targets including eliminating waits of over 18 months from referral to treatment by April 2023.⁵¹ The Referral to Treatment target means that patients should not normally wait more than 18 weeks from being referred to starting treatment, unless they choose to wait longer, or it is in their best interests to delay treatment - for example because of other health conditions.

However, NHS England has told us that delayed breast reconstruction is not covered by the Referral to Treatment target. This is because it is seen as a continuation of a planned treatment rather than a new treatment, as it happens after a mastectomy.⁵² Therefore, delayed reconstruction is not covered by the target in the Elective Recovery Plan. Despite the emphasis on the importance of addressing the long waits facing those whose treatment was disrupted by the pandemic, this plan fails to include any specific actions for breast reconstruction or risk-reducing surgery, which fall outside the category of high volume, less complex surgery.

NHS England has asked that Cancer Alliances both accelerate the rate at which they work through the backlog on delayed

breast reconstruction, and also work with their local trusts and ICSSs to deliver immediate breast reconstruction. However, it only suggests they seek opportunities to provide delayed reconstruction for those women who were unable to have surgery during the pandemic, with no clear direction on how to achieve this.^{53 54}

Due to the slow progress, ABS and BAPRAS have published a joint statement to emphasise the importance of recovering breast reconstruction services.

Action must be taken to ensure that patients waiting for delayed breast reconstruction are not waiting longer than other patients.

The Government could achieve this by incorporating delayed breast reconstruction within the Referral to Treatment waiting time target. Alternatively, a separate target could be set for delayed breast reconstruction.

Any target would need to apply from the point at which women decide they wish to have their delayed breast reconstruction surgery, or from when they are clinically fit for further surgery - whether that is following recovery from their mastectomy, treatment such as radiotherapy, or when other health conditions allow.

This will not only drive progress towards reducing long waits caused by the pandemic, but will also provide momentum for taking action to address the issues with access to free flap breast reconstruction.

Specific ways to help

Further support is needed to specifically address the backlog and long waits for breast reconstruction and risk-reducing surgery.⁵⁵ There are a number of ways this might be achieved.

Dedicated elective surgical hubs

To increase capacity during the pandemic, some regions set up ‘COVID-protected’ surgical cancer hubs to enable cancer surgery to continue.^{56 57 58} Subsequently, NHS England has promoted the use of dedicated elective surgical hubs, either as a distinct or ringfenced space within a hospital or on a separate site, to deliver elective procedures.⁵⁹ And the Royal College of Surgeons of England has endorsed these surgical hubs as an effective way to ensure the delivery of elective activity.⁶⁰

There are currently over 50 new surgical hubs set to open across England.⁶¹ NHS England has also committed £1.5 billion towards elective recovery services, which can be spent on this approach.⁶² Local trusts are currently considering how to best deliver these new surgical hubs to meet the needs of their own populations, which we recommend include breast reconstruction.⁶³



JANE'S STORY ‘I WAS REALLY SURPRISED WHEN I GOT THAT CALL...’

Jane was offered genetic testing after her sister died from breast cancer and a mammogram showed that her mum also had the disease. She had immediate reconstruction as part of her risk-reducing surgery.

When her test came back positive for the altered PALB2 gene, Jane was clear she wanted risk-reducing surgery. ‘Even before I knew my results, I knew what I’d do if I was carrying the mutation too,’ she says.

Fortunately, Jane went on to have a good experience of treatment and care, with clear communication at every stage, despite the pandemic.

‘The process wasn’t slow seeing as we were in a pandemic.’

‘I first saw the breast surgeon in August that year. I was really surprised when I got the call to say that they would do it. At the time, I was seeing everywhere that risk-reducing surgery was being cancelled because they were just concentrating on the cancer, which is understandable.’

‘Looking back at it, I think I was probably more relaxed because I was walking towards the cause of my risk. I wasn’t nervous. I know that sounds really, really silly, but it was kind of exciting, knowing it was being done.’

‘EVEN BEFORE I KNEW MY RESULTS, I KNEW WHAT I'D DO IF I WAS CARRYING THE MUTATION TOO.’

'I JUST WANT TO KNOW WHEN IT WILL BE HAPPENING SO I CAN MOVE ON WITH MY LIFE.'



**CARLIE-ANN'S STORY
'I HAD EVERYTHING SET UP FOR RECONSTRUCTION, GOT ALL THE PHOTOS AND SCANS... AND NO ONE HAS SAID ANYTHING SINCE'**

After being diagnosed with breast cancer in March 2020 and despite expecting to have a lumpectomy, Carlie-Ann ended up having a single mastectomy. Carlie-Ann missed out on immediate reconstruction and is still waiting for her reconstruction, because of the pandemic and ongoing recovery of reconstruction services.

Carlie-Ann spoke to her oncologist, and they wrote a letter to the plastic surgery department to highlight the impact it has had on her mental health. But it hasn't helped.

Despite implant-based reconstruction restarting locally, Carlie-Ann is still waiting for DIEP flap reconstruction.

'DIEP reconstruction and implants are done at different hospitals. I could possibly get it sooner if I wanted implants but I feel DIEP flap would give me better balance. It's had an impact on dating and my self-confidence. It's affected how I see myself.'

Carlie-Ann has had very little information on how long she'll be waiting for her reconstruction.

'I just want to know when it will be happening so I can move on with my life.'

'It is really tough, I've had self-esteem issues. I won a photoshoot last year. We did some normal shots and some with my scar. I could only choose one to keep and I picked the one with the scar, so I am trying to embrace my body, but it's not always easy.'

'I have tried putting normal pictures on my dating app but it's awkward as then I have to have a conversation about it at some point. I now use the photo from when I won the competition, which helps. It's hard as I just want the conversation to be light and flirty, but it affects how you come across.'

Continued use of the independent sector and weekend capacity

During the pandemic, NHS England also commissioned facilities in the independent sector to deliver dedicated ‘COVID-protected’ surgical cancer hubs.⁶⁴ As part of the recovery of elective services, weekend capacity also has already been used for lower priority breast surgery, such as reconstruction or risk-reducing surgery. Depending on local availability of the independent sector, which is largely situated in London and the South East, it may be possible to provide additional space and time for breast reconstruction through its continued use and use of weekend capacity in the independent sector and NHS.

A reconstruction rota

Another way to deal with the backlog would be to create a reconstruction rota.⁶⁵ Under this model, patients would be allocated to the next available list and surgeon rather than being referred to a specific consultant.⁶⁶ This may affect patient choice in relation to their surgeon, but it could also provide an option for those who want or need to prioritise the timing of their surgery. Patients who choose to stay with the surgeon they already know, should not be penalised for doing so.

RECOMMENDATION:

The backlog and long delays facing those awaiting breast reconstruction or risk-reducing surgery must be addressed.

NHS England should:

- Incorporate breast reconstruction within the Referral to Treatment target, so the timescales for recovery set out in NHS Elective Recovery Plan apply to it, and long waits are eliminated moving forward
- Work with Breast Cancer Now, ABS and BAPRAS to establish a plan of recovery for breast reconstruction services
- Support Cancer Alliances and ICSs to introduce or continue to deliver initiatives to address the backlog, such as dedicated elective surgical hubs, continued use of the independent sector, and reconstruction rotas.

Improving data collection

The HES database includes details of all hospital admissions, A&E attendances and outpatient appointments. Following the GIRFT review of breast surgery, work has been undertaken to agree new codes for breast surgery including reconstruction, alongside a manual to clarify their use. This will help to ensure that HES data accurately reflects the breast reconstruction that is being undertaken. These are expected to launch in April 2023.

Moving forward, data on breast reconstruction – such as rates of different types of reconstruction and outcomes – will also be available to trusts on the Model Health System, to help them drive improvements in patient care.

However, the analysis of the FOI requests undertaken to inform the content of this report highlights the variability of data collected across different trusts for example on waiting times for delayed breast reconstruction. This is vital in understanding issues with access and backlogs.

RECOMMENDATION:

Consistent data must be collected on the number of patients waiting for breast reconstruction and risk-reducing surgery, and how long they have been waiting, both locally and nationally.

NHS England should also include breast reconstruction in the single integrated audit programme for breast cancer.

CONCLUSION

Patients who choose reconstruction must have access to the surgery that is right for them – whether that is implant surgery or free flap surgery.

They should be able to choose an immediate reconstruction, or to delay surgery until the time is right for them. And if more than one surgery is required for a satisfactory outcome, they should be able to access that too – no matter where they live.

However, worrying gaps in everything from information and support to the number of trusts providing free flap surgery and surgical teams alongside the impact of disruption caused by the COVID-19 pandemic, mean that women's choices are being severely curtailed. This is having a sometimes devastating impact on their wellbeing, self-image, and self-esteem.

Action must be taken to address these challenges, reduce variation and improve the experiences of those choosing to have breast reconstruction.

To achieve this, NHS England should work in partnership with ICSs, Cancer Alliances and trusts, to implement the recommendations outlined in this report. They must also engage with stakeholders including Breast Cancer Now, ABS, BAPRAS and patients who are considering, waiting for, or who have had breast reconstruction, to ensure that the views of patients and health professionals are taken into account and to foster a coordinated approach.

'ACTION MUST BE TAKEN TO ADDRESS THESE CHALLENGES, REDUCE VARIATION AND IMPROVE THE EXPERIENCES OF THOSE CHOOSING TO HAVE BREAST RECONSTRUCTION.'

APPENDIX

Methodology and data sources

To help build a current picture of breast reconstruction services, we undertook a variety of work, including:

- Interviews and meetings with a range of healthcare professionals culminating in a summit on 27 April 2022 which brought together key stakeholders, including members of the charity sector, ABS, BAPRAS, and healthcare professionals. The purpose of the summit was to discuss the key issues affecting breast reconstruction and to explore potential solutions
- A UK-wide online survey of 2,586 people affected by breast cancer who had received or were awaiting breast surgery, including risk-reducing surgery and breast reconstruction. The survey ran between 30 March and 9 May 2022 and focused on experiences of breast surgery, in particular breast reconstruction
- Six interviews with people with breast cancer about their experiences of breast surgery
- FOI requests to hospital trusts across England asking about local restrictions and the current state of breast reconstruction services following the impact of the COVID 19 pandemic. The FOI requests were made to trusts on 24 May 2022 and responses were collected until 5 September 2022

The GIRFT review of breast surgery (2021) also provided a very helpful picture of access to breast reconstruction across England.

Breast surgery key terms

Mastectomy - A mastectomy is an operation to remove as much breast tissue as possible, either to remove breast cancer cells or to reduce the risk of breast cancer developing in the first place (risk-reducing surgery). A single mastectomy is when breast tissue is removed from one breast. And a bilateral (or double) mastectomy is when breast tissue is removed from both breasts.⁶⁸

Lumpectomy/Breast conserving surgery - A lumpectomy also known as a ‘wide local incision’ is where a surgeon removes only the cancerous tissue and a clear margin of tissue, while aiming to conserve as much healthy breast tissue as possible.⁶⁹

Risk-reducing surgery

There are some people who have an increased risk of developing breast cancer, including those who have inherited an altered gene that increases this risk. Those who are at the highest risk will be offered a range of approaches which can involve risk-reducing surgery, usually a bilateral (double) mastectomy.⁷⁰

Breast reconstruction

Breast reconstruction surgery is the creation of a new breast shape, or mound, using surgery. It may be done after removal of a whole breast (**mastectomy**) or part of the breast (**breast-conserving surgery**). Breast reconstructions uses different methods: implants (implant-based reconstruction), or tissue and fat from another part of the body (free flap reconstruction), or a combination of the two. A patient can also have bilateral breast reconstruction to both breasts.

Implant based reconstruction - This involves the insertion of an implant under the skin to help create the shape of a breast. There are a range of different types of implants (e.g. salt water, silicone, gel) and surgery may require one or two procedures. Further surgery may also be required later to replace an implant.

Pedicled flap reconstruction - This involves the use of tissue (skin, fat and muscle) from near the breast to rebuild part of the breast shape and includes using skin and fat on the chest adjacent to the breast (LICAP flaps) and skin, fat and muscle from the back (LD flaps). If a mastectomy has been performed an implant may also be necessary.

Free flap reconstruction

This involves the use of tissue (skin and fat) from other parts of the body (e.g. stomach, thighs, or buttocks) to rebuild the breast shape.⁷¹ Microsurgical techniques are used to connect the tiny blood vessels to the new site. This can be a more complex procedure and may require a longer recovery period. Free flap reconstruction can sometimes be referred to by the various different approaches to creating a flap eg the DIEP Flap (from the lower abdomen as in a tummy-tuck) and PAP Flaps (from the upper thigh) referring to the part of the body used to create the flap. Other types include transverse upper gracilis (TUG) or L-shaped upper gracilis (LUG) flap.

Balancing/symmetrisation surgery

- Sometimes after surgery, the reconstructed breast can be different in size and shape from the unaffected breast. While some difference is to be expected, even in women who haven’t had surgery, it is an option to have surgery on the previously unaffected breast if needed in order to create a better balance and sense of symmetry.

Immediate reconstruction

This is reconstruction that takes place at the same time as a mastectomy or lumpectomy.

Delayed reconstruction

This is reconstruction undertaken at a later stage, following initial breast surgery. This may be determined by the type of reconstruction, by subsequent treatment, and/or by the patient’s preference

Oncoplastic surgeon - Oncoplastic surgeons are trained in surgery to remove breast cancer and can perform therapeutic mammoplasty and local flaps – techniques which reduce the need for mastectomy. They also do implant-based reconstruction and symmetrisation or balancing surgery, but not free flap surgery, which is done by plastic surgeons.

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DON'T FORGET

We're here if you ever need to talk.

Our breast care nurses and highly trained staff on our **free Helpline** are here for you, whatever you're going through.

We're ready to listen on **0808 800 6000** or you can find information and support online at **breastcancernow.org**

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