

Written Evidence submitted by Breast Cancer Now (IBI0026)

About Breast Cancer Now

Breast Cancer Now is the charity that's steered by world-class research and powered by life-changing care. We're here for anyone affected by breast cancer, the whole way through, providing support for today and hope for the future.

Every year in the UK around 55,000 women and 370 men are diagnosed with breast cancer¹. It is estimated that 14,850 of the 55,000 women diagnosed with breast cancer each year in the UK undergo a mastectomy – with around 3,119 (21%) of these patients opting to have immediate breast reconstruction, and 1,485 (10%) having delayed reconstruction². There are also women at increased risk of developing breast cancer because of their family history who may choose to have mastectomy as risk reducing surgery.

Although not everyone who undergoes a mastectomy will opt for breast reconstruction for those who choose to have breast reconstruction it is an important part of their wellbeing and their recovery from breast cancer.

The National Mastectomy and Breast Reconstruction Audit published in 2011 highlighted the psychological importance that breast reconstruction can have. The audit found that reconstruction has an effect on body image and also sexual wellbeing. It also found that 47% of those who had either delayed or immediate reconstruction felt sexually attractive when unclothed most or all of the time compared to 15% of women who had a mastectomy³. This illustrates the importance reconstruction can have for body image and self confidence for those recovering from breast cancer who choose to have reconstruction.

Despite the importance breast reconstruction can have for body image, there are many ongoing issues that can impact patient access and choice. Our report *Rebuilding My Body* published in 2018 highlighted that despite NICE guidance⁴ there are still issues with women being able to access breast reconstruction⁵. In some CCGs in England there are restrictions that limit the time in which reconstruction can be completed and limits on the number or type of operations.

Breast reconstruction can be a complex procedure that can involve many operations. Whilst every effort will be made to ensure the best outcome for the patient with as few procedures as possible, patients should not be penalised if further surgery is required to achieve a satisfactory result or because of complications. Limits on operations has implications for patient choice as it may deter women from certain types of reconstruction.

There are also restrictions in some CCGs on balancing procedures for the unaffected breast. Access to balancing procedures can be important for the final outcome as a reconstructed breast may not

¹ Average total of UK invasive breast cancer cases between 2014 and 2016. (England - Cancer registration statistics, England. Office for National Statistics. Scotland - Cancer statistics, breast cancer. Information Services Division, NHS National Services Scotland. Wales - Breast Cancer, Welsh Surveillance and Intelligence Unit. Northern Ireland - Northern Ireland Cancer Registry, breast cancer)

² National Mastectomy and Breast Reconstruction Audit, 2011, available at <https://files.digital.nhs.uk/publicationimport/pub02xxx/pub02731/clin-audi-supp-prog-mast-brea-reco-2011-rep1.pdf>

³ Ibid

⁴ NICE Guideline [NG101] [Early and locally advanced breast cancer: diagnosis and management, 2018, available at https://www.nice.org.uk/guidance/ng101/chapter/recommendations](https://www.nice.org.uk/guidance/ng101/chapter/recommendations)

⁵ Breast Cancer Now, *Rebuilding My Body: Breast Reconstruction in England, 2018* available at https://breastcancer.org/sites/default/files/rebuilding_my_body_report_june_2018.pdf

match the size and shape of the unaffected breast. Not routinely funding these procedures in all areas means that some women do not have the same level of choice and may not be happy with the result of reconstruction.

Some areas have put time limits on breast reconstruction which can impact access to delayed reconstruction. Although many reconstructions carried out are immediate, some women opt for delayed reconstruction. There can be many reasons why individuals may opt for delayed reconstruction including patient preference, treatment and co-morbidities. Time limits are another example of how restrictions in some areas on breast reconstruction can limit patient choice.

As part of the transition of CCGs to ICSs it is vital going forward that existing restrictions on reconstruction are lifted to ensure that all areas comply with NICE guidance and ensure everyone has access to the breast reconstruction they need, when they need it.

There are also challenges with access to some types of breast reconstruction particularly where tissue is used from other parts of the body known as autologous or free flap reconstruction. More than 1 in 5 breast reconstructions currently use free flap⁶. However, despite widespread use findings from the recent publication of the Breast Surgery Getting It Right First Time report showed that there is local variation in access to free flap reconstruction with some areas where there is no free flap service. This has implications for patient choice as some women who may prefer or be better suited to free flap reconstruction may have implant based reconstruction or may need to opt for delayed reconstruction instead of immediate in order to have their desired type of reconstruction. Lack of choice can add to delays or lead to a result from the surgery that the patient may not be happy with. Therefore it is vitally important that there is equitable access to free flap reconstruction to ensure that all patients considering reconstruction are able to choose the type that is right for them, at the right time.

The Covid 19 pandemic has had a huge impact on breast reconstruction. During the first wave of the pandemic breast reconstruction was paused. We estimate that over 1000 women will have missed out on immediate reconstruction during this time, and around another 500 will have had their delayed reconstruction delayed further⁷. Although breast reconstruction surgery has resumed, it is likely there continues to be impacts on waits for reconstruction due to the current backlog affecting elective surgery. There were already waiting lists of up to two years for delayed reconstruction in many hospitals prior to the pandemic.

“I was diagnosed with a new primary breast cancer four days into the first lockdown (I had it in July 2017 too). I had a mastectomy five days later but immediate reconstruction was not on offer, due to COVID. I was scheduled for a reconstruction October 2020, but that got postponed due to COVID. It was rescheduled to January 2021 was cancelled again, due to COVID. I now have no idea when it will happen. I appreciate a delayed reconstruction is not urgent cancer surgery, but emotionally and psychologically, the reconstruction is very important to me. I now have no idea at all when it will happen.” Rosemary from Northampton

“I was going to have a double mastectomy with immediate breast reconstruction in April, however, I got a call saying that reconstructive surgery had to be suspended due to the pandemic. It was one of the worst periods since my diagnosis and really difficult to come to terms with the fact that

⁶ Getting it Right First Time, Breast Surgery- GIRFT Programme National Specialty Report, 2021

⁷ In a normal four-month period there would be 4,952 women to have mastectomies, with just over 1000 (1040) having immediate reconstruction and around 500 (496) having delayed reconstruction. <https://files.digital.nhs.uk/publicationimport/pub02xxx/pub02731/clin-audi-supp-prog-mast-brea-reco-2011-rep1.pdf>

coronavirus had got in the way of my plans. Then my mastectomy was brought forward to the first weekend of lockdown and I had only four days to get used to the idea of being flat. I did spend those 4 days frantically trying to find somewhere and someone who would do my reconstruction, though to no avail. It felt like I was also losing my breasts to COVID-19, not only cancer.” **Laura from Cambridge**

We have heard from many women during the pandemic, including the case studies above who have experienced disruption and uncertainty to their reconstruction surgery. It has been difficult for many women with breast cancer who have been awaiting breast reconstruction surgery to deal with delays caused by the pandemic. For many it has had an impact on their body image, self-esteem and confidence. Our survey on the impact of Covid on breast cancer services found that of those that experienced changes to their reconstructive surgery nearly half (48%) told us they were unhappy with their body image, and 59% were concerned that they would need more operations as they were unable to have reconstruction at the same time as their mastectomy⁸. This adds to that fact that for many people with breast cancer the pandemic has impacted their mental health. Our research found that 60% of people with breast cancer feeling stressed or anxious due to the impact of the pandemic.

“I struggle every day trying to adjust to the changes after my mastectomy and I still avoid looking at my body. It was especially hard during lockdown when I had so much time to think, which really impacted my mental health. Breast reconstruction is not just cosmetic surgery – for me, it is fundamental to my body image. Waiting for this major surgery makes it very difficult to move on with my life and get any sort of closure from my breast cancer. I’m always wondering whether plans I make may then need to be re-arranged were surgery to be possible.” **Janet, Vale of Glamorgan**

Although breast reconstruction has resumed, the pandemic has continued to impact access. While we understand that immediate reconstruction is happening where possible, the current wave of the Omicron variant has led to some trusts pausing non-urgent surgery which will further slow clearing the backlog of delayed reconstruction⁹. The guidance on surgical prioritisation has given delayed breast reconstruction the lowest priority¹⁰ which will add to delays to clearing the backlog of those currently awaiting reconstruction. As a result there are likely increasing numbers of women who are waiting longer for their breast reconstruction which may impact their body image and wellbeing.

It is vital as part of the elective recovery plan that action is taken to help address the backlog of those waiting for delayed reconstruction and to safeguard services from further delays and disruption.

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⁸ Breast Cancer Now, Press Play: Getting and Keeping Breast Cancer Services Back on Track, 2020, available at https://breastcancernow.org/sites/default/files/final_breast_cancer_now_press_play_report.pdf

⁹ <https://www.bbc.co.uk/news/uk-england-manchester-59878179>

¹⁰Federation of Surgical Speciality Association, Clinical Guide to Surgical Prioritisation in the recovery from the Coronavirus Pandemic, November 2021, available at https://fssa.org.uk/userfiles/pages/files/covid19/prioritisation_master_261121.pdf