

## RESEARCH ARTICLE

# Exploring the Lived Experience of Undergoing an Immediate Versus Delayed Deep Inferior Epigastric Artery Perforator (DIEP) Flap Reconstruction in Women Who Require Post-Mastectomy Radiotherapy.

### Authors

Rachel L O'Connell, FRCS(Gen)<sup>1\*</sup>, Jennifer E Rusby, FRCS(Gen)<sup>1\*</sup>, Amrit Sagha BSc(Hons)<sup>2\*</sup>, Sofia Georgopoulou, PhD<sup>2</sup>, Anna M Kirby, FRCR<sup>3</sup>, Paul A Harris, FRCS(Plast)<sup>4</sup>, Stuart E James, FRCS(Plast)<sup>4</sup>, Kieran Power, FRCS(Plast)<sup>4</sup>, Kelvin WD Ramsey, FRCS(Plast)<sup>4</sup>, Theresa Wiseman PhD<sup>2</sup>,

### Affiliations

- <sup>1</sup>. Department of Breast Surgery. The Royal Marsden NHS Foundation Trust, Sutton.
  - <sup>2</sup>. Department of Applied Health Research. The Royal Marsden NHS Foundation Trust, London.
  - <sup>3</sup>. Department of Clinical Oncology. The Royal Marsden NHS Foundation Trust & Institute of Cancer Research, Sutton.
  - <sup>4</sup>. Department of Plastic Surgery. The Royal Marsden NHS Foundation Trust, London.
- \* Denotes joint first authors

### Corresponding author:

Dr Jennifer Rusby,  
Department of Academic Surgery, The Royal Marsden NHS Foundation Trust, Fulham Road, London, SW3 6JJ  
Telephone: 02073528171  
Email: [jennifer.rusby@rmh.nhs.uk](mailto:jennifer.rusby@rmh.nhs.uk)

**Financial Disclosure Statement:** Miss Rachel O'Connell was funded by a 1 year Royal College of Surgeons of England Research Fellowship.

This paper represents independent research funded by the National Institute for Health Research (NIHR) Biomedical Research Centre at The Royal Marsden NHS Foundation Trust and the Institute of Cancer Research. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. There are no commercial associations of financial disclosures.

## **Abstract**

### **Introduction**

Post-mastectomy radiotherapy (PMRT) is recommended to women at high risk of local recurrence. There is a paucity of published work on the experience of women who undergo deep inferior epigastric perforator (DIEP) flap breast reconstruction in the context of requiring PMRT. The aim of the study was to explore and understand the patient experience of these women.

### **Methods**

Purposive sampling was used to identify patients who had undergone an immediate reconstruction with PMRT and women who had undergone a delayed reconstruction after PMRT. Purposive sampling was used to identify and invite women to participate in the study. Semi-structured interviews were conducted using a grounded theory approach with a topic guide which was derived from relevant literature.

### **Results**

Twenty women participated in the study. Ten women had undergone immediate reconstruction followed by PMRT and 10 women had undergone delayed reconstruction after PMRT. The results suggest that, regardless of the surgical pathway or the consequences of treatment, overall women were satisfied with the treatment decision they had made. Patients described the challenges around decision-making and their post-operative experience. However, patients were grateful to have had a breast reconstruction and in the most part happy with the treatment pathway they underwent.

### **Conclusion**

The findings of this study suggest that women are motivated by a variety of factors when presented with the choice of immediate versus delayed breast reconstruction and can justify the treatment path they have taken. This study highlights the importance of discussing reconstruction options in terms of context of a person's life and coping strategies. Patients appeared to use self-regulation in their behaviour to cope with their illness threat and decision-making. The women who chose delayed reconstruction were motivated by the delayed gratification of having a reconstruction that had not been subjected to PMRT.

### **Introduction**

In the UK, 53% of women with symptomatic breast cancer and 27% of those with screen-detected breast cancer are treated surgically with mastectomy<sup>1</sup>. During surgical decision-making, some women will be advised that undergoing a mastectomy is required for effective treatment of their cancer while others will be offered the choice between wide local excision and mastectomy. Once the decision to undergo a mastectomy for

breast cancer is taken, further consideration is necessary regarding whether to undergo breast reconstruction, and if so, if it should be an immediate (at the same time as the mastectomy) or a delayed procedure.

The benefits of breast reconstruction have been demonstrated in a significant number of studies with reported improvements in a variety of patient-reported outcomes, such as mental health, aesthetic outcome, satisfaction

rates, self-esteem, sexuality, and body image following mastectomy<sup>2-10</sup>. The options and advantages available to patients through breast reconstruction after breast cancer treatment have been described by patients, breast surgeons, oncologists, reconstructive surgeons<sup>11,12</sup>, as have the risks. As a result, women often opt for breast reconstruction following mastectomy<sup>13</sup>. In the UK immediate breast reconstruction rates range between 13.1-36.7%<sup>14</sup>.

Adjuvant post-mastectomy radiotherapy (PMRT) is offered to women deemed to be at high risk of chest wall recurrence<sup>15</sup> and is one of the factors which may influence the type and timing of breast reconstruction offered to patients. The perceived detrimental effect of radiotherapy on an immediate breast reconstruction and the “one-off” nature of autologous reconstruction – taking a section of tissue from one area of the patient’s body — most often their abdomen — and relocating it to create a new breast mound — leads some surgeons to recommend a delayed reconstruction after a simple mastectomy or to use a temporising implant (tissue expander) also known as ‘delayed-immediate reconstruction’<sup>16-18</sup>. This would then be followed by autologous reconstruction after radiotherapy. There remains some uncertainty in the literature about the impact of radiotherapy on autologous reconstructions<sup>19-21</sup>. Initially, small case series suggested that radiotherapy was detrimental to the autologous reconstruction, but more recent, larger series have challenged this view<sup>22-24</sup>.

To date there is a paucity of published work on the experience of women who undergo autologous breast reconstruction in the context of requiring PMRT and the effect this has on the appearance and feel of the reconstruction. The pathways of immediate and delayed reconstruction are very different and warrant further investigation to aid clinicians and patients in their decision-

making. The aim of this study, therefore, was to use qualitative methods to investigate patients’ lived experience of undergoing a mastectomy and immediate autologous breast reconstruction followed by PMRT as well as exploring the experience of women who have undergone a mastectomy, with or without tissue expander, followed by PMRT and later a delayed autologous reconstruction. It was deemed important to understand similarities and differences in experience.

### **Research design and Methods**

As the aim of the study was to explore and understand the patient experience, a qualitative design was chosen. More specifically, a grounded theory approach<sup>25-27</sup> was taken because of the lack of research in this area. This methodology involves the construction of hypotheses and theories through the collecting and analysis of data.

### **Context**

Regional ethical committee approval was obtained for this study and registered (clinicaltrials.gov NCT03072316) as part of a larger body of research on autologous reconstruction. Women who participated in the larger clinical study were those who had undergone a delayed or immediate deep inferior epigastric perforator (DIEP) flap in the 6 years prior to recruitment i.e. had undergone surgery between 2009 and 2014. In the earlier part of this time frame, most breast and plastic surgeons were advising against autologous reconstruction if post-mastectomy radiotherapy was anticipated. In this situation, delayed reconstruction or tissue expander was advised. Some women underwent a mastectomy and immediate DIEP reconstruction but had more extensive disease than anticipated, leading to a recommendation for post-mastectomy radiotherapy of the breast reconstruction. Towards the end of the time frame, immediate DIEP flap reconstruction was

being offered to selected women undergoing unilateral mastectomy even if PMRT was anticipated.

### **Recruitment**

At the time of their participation in the larger study, patients were asked if they would be willing to attend an in-depth interview at a later date. Those who had agreed were then eligible to be contacted by telephone to identify a suitable time for the interview. Purposive sampling was used to ensure variation of age, immediate reconstruction and delayed reconstruction with and without tissue expander. Purposive sampling was used for the identification and selection of information-rich cases for the most effective use of limited resources.

### **Data collection**

Semi-structured interviews were conducted by a medically qualified researcher with an interest in oncological breast surgery (RO). Following training and supervision in qualitative research methods, the researcher used a topic guide that was derived from relevant literature and agreed upon with the other authors. The topic guide explored issues related to decision-making, undergoing treatment and satisfaction with cosmetic outcome.

All interviews were undertaken in a private room or via telephone depending on the participant's preference. The interviews were digitally audio-recorded, transcribed verbatim and anonymised using pseudonyms to protect participant confidentiality.

### **Analysis**

The analysis ran alongside data collection as an iterative process that informed further purposive sampling in order to enrich the data. The purpose of the analysis was to describe the participants' opinion and to develop theoretical explanations for these.

The interviews were analysed by two authors (RO and AS) independently reading the transcripts in detail and codes were assigned to give meaning to segments of the text. Emerging codes were grouped into themes and discussed (RO, AS, TW) and then explored in subsequent interviews. The analysis was undertaken using the constant comparison technique of grounded theory whereby data were examined for differences and similarities within the themes, considering the patient context<sup>27</sup>. The initial codes were modified, and new codes added as the project progressed. New data were compared with previous interviews to identify the similarities and differences.

### **Findings**

#### **Participant demographics**

Twenty women who had undergone autologous deep inferior epigastric perforator flap (DIEP) breast reconstruction participated in the study. Ten of the women had undergone immediate reconstruction followed by PMRT. Ten women had undergone delayed reconstruction, five of whom had had a simple mastectomy and PMRT before the reconstruction and five underwent a skin-sparing mastectomy with insertion of a tissue expander, PMRT and subsequent reconstruction.

The median age at the time of interview was 55 years (range 42-74 years) with a median time between DIEP reconstruction and the interview of 31 months (range 16-49 months).

#### **Theme 1: Making the decision**

All participants reported discussing the surgical options for reconstruction with their breast and plastic surgeon. This was appreciated by the patients although some felt that there was not sufficient time between diagnosis and surgery.

“There wasn't a lot of time to think...you are not necessarily

in the right state of mind or informed enough and that isn't anything to do with the doctors - just the nature of this" (participant 1, immediate reconstruction).

Whereas others felt that they had enough time to discuss and process the information and come to the right decision for them as an individual.

"Mr X went through everything step by step...he showed me photographs...he knew exactly what I wanted...he understood where I was coming from..." (participant 14, delayed reconstruction).

Although all the patients discussed the reconstructive options, two patients who underwent a delayed reconstruction reported being advised against an immediate reconstruction. In one case, the patient recalled not being given a choice with regards to having an immediate autologous reconstruction and then PMRT.

"I seem to think that they said this is your best option [delayed reconstruction] and I took it" (participant 13, delayed reconstruction).

"He did say to me that he wouldn't do the reconstruction at the time [of the mastectomy]" (participant 14, delayed reconstruction).

Women who underwent immediate reconstruction described wanting to have their breast cancer and reconstruction surgery completed in one procedure and getting on with their life rather than delaying the reconstruction until a later date. There was a sense that undergoing a delayed reconstruction was prolonging the period of undergoing breast cancer treatment and

increased the time taken to get back to "normality."

"It was the right thing just to get it all over with, quite frankly" (participant 2, immediate reconstruction).

"I was going under the knife, you might as well just get it done and sorted...so I was quite excited about the prospect of getting it all done at once" (participant 8, immediate reconstruction).

For these women, the prospect of having a period of time with a flat chest wall or temporary implant was not something they wished to do.

"I didn't want to go and have another operation a year later...I didn't want to go around with a very disfigured chest" (participant 3, immediate reconstruction).

"Very difficult [the idea of a delayed reconstruction] because every single day you would have a reminder...you'd have a flat bit there" (participant 2, immediate reconstruction)

"I have gone in [to the operation theatre] with two boobs and I want to go out with two boobs" (participant 4, immediate reconstruction).

Whereas women who underwent a delayed reconstruction often did not feel so strongly about having an immediate reconstruction and felt that a delayed reconstruction would give the best aesthetic outcome.

"An immediate reconstruction was on offer, but radiotherapy could be detrimental, I was sorely tempted but probably logic would take over...I'll wait and get the best result

possible” (participant 14, delayed reconstruction)

Other women who had a delayed reconstruction did not feel ready to contemplate reconstructive surgery at the time of mastectomy and preferred to focus on the oncological part of the treatment rather than the reconstruction.

“I think I was in such a shock and trauma that really I didn’t think about cosmetics I was just thinking survive, survive” (participant 20, delayed reconstruction).

### **Theme 2: Experience in the post-operative period**

The women in the delayed reconstruction group described their experience of living with a tissue expander or flat chest wall. Two of the five women who underwent a temporising implant reported significant pain and discomfort associated with the tissue expander.

“It was hideous, it just felt like someone was literally pulling my left breast constantly” (participant 11, delayed reconstruction with tissue expander).

“I hated it...it was hard, it was uncomfortable...I remember it being difficult sleeping, it felt like a lump of concrete” (participant 16, delayed reconstruction with tissue expander).

Most women who had a delayed reconstruction wanted to undergo the DIEP reconstruction as soon as possible, although most were advised to wait at least one year after radiotherapy.

“I was desperate for this [delayed reconstruction], I wanted this operation...let’s

get it done” (participant 14, delayed reconstruction).

“The mastectomy was the worst thing ever and the waiting [for reconstruction] was horrible” (participant 15, delayed reconstruction).

However other women who had a delayed reconstruction reported adapting well to having a flat chest wall and did not feel in a rush for the reconstruction.

“I think that within three months I was almost back to normal” (participant 13, delayed reconstruction).

There were a variety of responses to the experience of undergoing the DIEP reconstruction surgery, some found it relatively easy, however, for others the experience was more debilitating during the recovery period.

“My recovery was really good...don’t recall any pain in the breast at all” (participant 4, immediate reconstruction).

“I couldn’t move a millimetre...she [nurse] had to wash me and brush my teeth I couldn’t do anything, it was quite a shock” (participant 20, delayed reconstruction).

Some of those that had undergone delayed reconstruction noted that the reconstruction operation was a much larger operation compared to the initial simple mastectomy.

“[The mastectomy operation] wasn’t as bad as I anticipated. I think the latter one, the reconstruction was [a] much more severe operation” (participant 20, delayed reconstruction).

### **Theme 3: Being whole again.**

All women who underwent a delayed reconstruction felt that undergoing the



reconstruction had a profound effect on them. Several women described a feeling of regained femininity and their physical body being 'whole' again.

"I got back my femininity...I felt like I had recovered my body when I had the reconstruction" (participant 13, delayed reconstruction).

Having the reconstruction appeared to give women confidence in their physical appearance.

"[I] chucked the horrible bras, chucked the frumpy tops...from the minute I got as I say 'rebuilt' it was just...better and better every single procedure" (participant 14, delayed reconstruction).

"I looked down, you know, and I do remember feeling really, really pleased and relieved" (participant 4, immediate reconstruction).

"I can honestly tell you it was quite reassuring.....that I still, albeit a far from perfect, but to still have a breast there" (participant 5, immediate reconstruction).

All the women who underwent an immediate reconstruction and PMRT were asked if they had noticed any change to the size, shape, texture of the reconstructed breast since radiotherapy. Seven of the ten women had noticed some hardening or lumps develop in the breast after the radiotherapy. Some of the women had been concerned that the lumps could represent recurrence of breast cancer, however they were all reassured after being seen in the breast surgery clinic, that these changes were fat necrosis.

"I still have lumps in there, one of which alarmed me, so I went to see my surgeon and

had a scan, and it is just fat necrosis" (participant 3, immediate reconstruction).

"Before I had the radiotherapy...it just felt sort of natural...but it certainly feels quite hard now" (participant 2, immediate reconstruction).

"The tissue has slightly got harder but otherwise no, fine...just going to live with it" (participant 7, immediate reconstruction).

None of the women who underwent an immediate reconstruction reported changes in the overall shape or appearance of their breast reconstruction sufficient to cause dissatisfaction. They all appreciated that radiotherapy was part of the oncological treatment for the breast cancer and that any changes were a side-effect of that.

From the whole cohort of patients, some women found that having an asymmetrical appearance of the breasts to be problematic and were grateful to have the opportunity to undergo symmetrisation.

"I've got one breast there and one down there...very very noticeable...never let anyone else [apart from my husband] see it" (participant 2, immediate reconstruction).

Whereas other patients felt that they did not want or need to undergo symmetrising surgery, despite being offered it.

"I don't care because sometimes it is almost like a badge of honour.... I've got slightly wonky breasts but...if that's the worst of it then you know I'm quite lucky" (participant 3, immediate reconstruction).

#### **Theme 4: Acceptance of decision and timing of breast reconstruction**

All except one participant said that they were satisfied with the surgical pathway they underwent. Several of the women felt that their reconstruction was not perfect but accepted that the decision made was made with the best intentions and information during a stressful time. For example, one of the patients who underwent an immediate reconstruction has accepted that the radiotherapy has caused some change to the reconstruction, but it was necessary for her treatment.

“It was a very good result until I had the radiotherapy, but no it’s because cancer is such a big thing you just accept where you are really” (participant 2, immediate reconstruction).

When the women were asked if they would have preferred to have undergone one of the alternative pathways, all felt that they had made the correct decision for them and seemed to rationalise why the alternative would not have been right for them.

“I think if I had the temporary implant...then was still waiting for the final bit of surgery, actually that final bit of surgery is still a very big bit of surgery” (participant 3, immediate reconstruction).

“I think having that waiting over me [to undergo delayed DIEP reconstruction] would have certainly been much more at the forefront of my mind” (participant 4, immediate reconstruction).

“Here is the brand-new breast [which is not exposed to radiotherapy] that I have been given .... so actually, yeah this is the right way round”

(participant 13, delayed reconstruction).

#### **Discussion**

Post-mastectomy radiotherapy (PMRT) has been shown to have survival advantages for women at high risk of chest wall recurrence following primary treatment for breast cancer<sup>28, 29</sup>. However, the perceived detrimental effect of PMRT on immediate breast reconstruction leads some surgeons to recommend delayed reconstruction after mastectomy with a view to planned exchange to autologous reconstruction after radiotherapy. A review of the literature suggests that there are no significant differences in measurable post-operative complications though there is some evidence of differences in satisfaction<sup>30, 31</sup>. However, to date there has been a paucity of published work on the lived experience of women who undergo autologous reconstruction. This study set out to address the gap in the literature and compare the lived experience of those who received immediate (pre PMRT) with women who underwent delayed reconstruction (post PMRT). There were four main themes of data: (a) “making the decision”, (b) “post-operative experience”, (c) “being whole again” and (d) acceptance of the decision and timing.

The findings suggest that, regardless of the surgical pathway or the consequences of treatment, overall women were satisfied with the treatment decision they made. It was clear from the women’s accounts that both treatment pathways presented physical and psychological challenges. Arguably, a recent breast cancer diagnosis may cause significant stress and anxiety that can complicate a patient’s decision-making for immediate breast reconstruction. The added psychological burden could compromise patients’ abilities to process information and to make informed choices<sup>32</sup>. However, only one of the women expressed decision regret



regarding having an immediate reconstruction with PMRT. The women justified their decisions by either reflecting on the positive aspects of the treatment option they received or highlighting the negative implications of the alternative.

The pathway and rationale of the participants' decision-making process can be understood when considered in the context of psychological theory namely, self-regulation. Self-regulation is the core concept of the Common-Sense Model (CSM) proposed in seminal work by Leventhal et al. (1980).<sup>33,34</sup> CSM provides a framework for describing and understanding the processes involved in the initiation and maintenance of behaviours to cope with illness threats. The model posits that in order to cope with an illness outcome, patients are likely to adopt coping procedures that focus on managing the problem. These coping strategies are influenced by both patients' beliefs about their illness (e.g., the severity of it or the likelihood of a cure/remission) but also the belief in their own confidence in their ability to cope effectively with an illness threat.

Applying this theory to the current study would mean that if a patient perceives that a delay in undergoing reconstructive surgery would have significant negative consequences on their life, they will potentially opt for a problem-focused health action that would involve immediate reconstruction. The decision would also be driven by their perceived self-efficacy i.e., the degree to which they feel confident that they can cope with the delay. If they felt that they are not able to cope with the consequences of delaying the procedure such as having flat chest wall, they would likely choose to have the reconstruction at the time of the mastectomy surgery. Alternatively, if a patient felt that an immediate reconstructive procedure would add to their burden, they

might choose an avoidant coping strategy i.e., delaying surgery. This was the case in the current study which showed that women who had opted for immediate reconstruction justified their decision saying that undergoing one operation was better than having two. There is evidence in the literature to show that individuals are more likely to engage in health behaviours in response to a perceived threat when their motivation and self-efficacy are high<sup>35</sup>.

A further potential factor inherent in decision-making, pertains to the quality and type of communication between patients and their clinician. Shared-decision making has been shown to enhance patient involvement and improve quality of life in women with breast cancer<sup>36-40</sup>. In the shared-decision-making model, both physician and patient are engaged in interactive discussions to develop a treatment plan based on patient preferences and values<sup>41-44</sup>. The physician's role is to facilitate communication and to incorporate these preferences and values within evidence-based medicine. This shared interaction builds rapport between patient and doctor and promotes a culture of trust in arriving at a joint decision.

Ashraf et al.<sup>44</sup> found that most patients in their study had adopted an informed or a shared-decision-making approach rather than a paternalistic approach when interacting with their clinicians about breast reconstruction. Both "informed-consumerist" and "shared decision" groups reported higher satisfaction and quality of life outcomes compared to those patients who preferred a paternalistic decision-making approach i.e., leaving the decision-making solely to their clinician rather than being actively engaged in the process themselves.

A systematic review by Flitcroft et al.<sup>45</sup> reported that many women were not provided with information about breast reconstruction, and that information was not always

presented in a manner they could understand. However, it was not clear whether this was due to omission of information by the surgeon or due to women's inability to recall a discussion that occurred. In the current study, all the women had engaged in a discussion with their breast and plastic surgeon. The data reflect that the process of decision-making was variable, with some patients offered the 'best option' or the surgeon's opinion of what they would do, whilst other patients were offered an open choice. As described in the introduction towards the end of the time frame, immediate DIEP flap reconstruction was being offered to selected women regardless of the need for PRMT, whereas at the beginning there was more caution in offering immediate reconstruction if PMRT was anticipated.

Restoring normality, both physically and psychologically, was a fundamental driver for the women seeking immediate reconstruction, avoiding the need for a second operation and being able to get back to their "normal", quicker. Immediate reconstruction resulted in the maintenance of their physical appearance which also reduced the physical reminder of cancer. Whilst body image was a less important factor in the treatment decision-making stage for those that underwent delayed reconstruction, our findings are consistent with earlier research, which suggests that women are unable to restore their body image until breast reconstruction is completed<sup>46</sup>.

At the time these participants underwent surgery, the perception among surgeons was that radiotherapy would harm an autologous reconstruction and delayed or delayed-immediate reconstruction was often advised. Those who accepted this recommendation for delayed reconstruction might have been motivated to do so by feelings of delayed gratification with the prospect of achieving better results<sup>47</sup>. Delayed gratification lies within the context of self-control and is

defined as the ability to tolerate longer delays in order to achieve a more satisfactory reward as compared to an immediate less satisfactory reward. A key concept in this process is weighing the costs and benefits associated with an immediate versus a delayed action. If an individual is confident that delaying an action will lead to greater rewards, they are more likely to do so. This theory links to self-regulation and feelings of motivation and self-efficacy described previously and can help explain the pathways of participants' decision making regarding delayed versus immediate reconstruction and satisfaction with the decision and its timing<sup>45, 47</sup>. This was evident in the differing viewpoints of the women who had a delayed reconstruction were more positive and felt that they had regained their femininity. Whereas those that had immediate simply had maintained their body image and may, therefore, not have felt as satisfied as the delayed group. This is paralleled by quantitative results from the main study, published previously<sup>30</sup>.

A limitation of this study is that it is small and included women recruited only from one centre so findings may not be generalisable to other populations. In addition, participants attended the interview at significantly different time points post-reconstruction surgery which might have had an impact on their responses (16-49 months). Interviews held over the telephone might also have contributed to varying responses as it might have felt less personal to participants as compared to face-to-face interviews.

## **Conclusion**

The findings of this study suggest that women are motivated by a variety of factors when presented with the choice of immediate versus delayed breast reconstruction and can justify the treatment path they have taken. The key finding that emerged from the present research highlights the importance of discussing options in terms of context of a

person's life and coping strategies. This will contribute significantly to acquiring a deeper understanding of women's reasons for choosing immediate or delayed breast reconstruction and can, subsequently, assist clinicians to support women with making choices most aligned with their individual values and needs. Insight into women's particular needs, beliefs and values can help towards supporting them in adopting effective coping strategies that might

contribute to improving the decision-making process but also enhance long-term outcomes and consequences of treatment choice.

### **Acknowledgements**

Miss Rachel O'Connell was funded by a 1 year Royal College of Surgeons of England Research Fellowship.

We acknowledge the assistance of Mr Jon Knox, Advanced Nurse Practitioner, and plastic surgery.

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