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# Prosthetic Realities, Prosthetic Futures: Challenging the status quo of external breast prosthesis design

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University of Plymouth

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**UNIVERSITY OF  
PLYMOUTH**

**PROSTHETIC REALITIES, PROSTHETIC FUTURES:**

**Challenging the status quo of external breast prosthesis design**

by

**ROSIE BRAVE**

A thesis submitted to the University of Plymouth  
in partial fulfilment for the degree of

**RESEARCH MASTERS**

School of Art, Design & Architecture

**June 2021**

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*“Nobody can control cultural processes. But designers can and should become cognizant of the conversations that enable them to create their designs, continue well after they have done their part, and ultimately impact a culture.” - Krippendorff (2007)*

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## **AUTHOR'S DECLARATION**

At no time during the registration for the degree of Research Masters has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

This research was financed by the 3D3 Centre for Doctoral Training.

Word Count: 22,063

A handwritten signature in black ink, appearing to read 'R. B. Baw', with a long horizontal flourish extending to the right.

Signed:

Dated: 17 June 2021

## **PROSTHETIC REALITIES, PROSTHETIC FUTURES:**

### **Challenging the status quo of external breast prosthesis design**

Rosie Brave

#### **ABSTRACT**

This practice-based research identifies the need and opportunity to update the design approach used in the production of external breast prostheses (EBP) for women post mastectomy.

Spurred by accounts of some women's negative experiences with their EBP, this research took influence from colour psychology, emotional design and consumer psychology to explore the potential to create a satisfying and transformative product and user-experience.

Drawing on grounded theory, design ethnography and human-centred design practices, an iterative, empathic and participant-centred design process and methodology emerged. Insights from interviews, cultural probes, co-design activities and solo practice were combined to inform the making of speculative prosthesis prototypes that could advance the discourse of EBP.

The aesthetics of prosthetics is a nascent research field, with some literature focussed on prosthetic limbs and a lack of attention on the prosthetic breast. Current external breast prostheses are semi-realistic or highly realistic and, as such, can keep wearers focussed on the absence of their breast(s) rather

than new opportunities for expressing identity - opportunities already available to wearers of limb prostheses.

This research concludes that through empathising and designing with wearers, designers can improve the EBP so that it better meets the diverse needs and desires of women and provides the potential for positive associations for those women who are currently dissatisfied with their prosthesis.



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## CHAPTER 1: INTRODUCTION

### 1.1 Thesis introduction

My first encounter with women's experiences of external breast prosthesis (EBP) use was around 6 years ago, when speaking with my then colleague, Sam Jackman. Until this point, I had given no thought to what happened to women after they received a breast cancer diagnosis, did not know the word "mastectomy" and was not aware that external breast prostheses (EBP) even existed. Hearing about Sue Jackman's experience via her daughter, I learned about mastectomy and the option to avoid reconstructive surgery by wearing an EBP inside a bra.

Sue's experience was that the EBP felt heavy and wobbly and "looked like a beige blancmange". Sue did not find it comfortable to wear and did not like the look of it and therefore rarely uses it.

Sam told me she and her mother did not understand why the EBP needed to look the way it did – it was trying to look like a breast but not fooling anyone. Sam wondered why it could not be someone's favourite colour, why even could it not be pink leopard print? This question set my imagination racing as I had already begun to explore colour psychology, surface-pattern design and customisation of products. I knew that limb prostheses were being customised in the USA and I wondered what it would be like if the same service could be made available for prosthetic breasts.

This thesis – the written document and the practice that informs it – considers both the current realities of external breast prosthesis and the future possibilities, if

alternative design approaches are adopted in their production.

In this first chapter, I introduce the reader to the external breast prosthesis (EBP), the wearer and the context in which EBPs are made, worn and understood. I share how my research aims and objectives have shifted in response to the nature of people-centred practice. I situate my work within a wider body of research and practice, defining key terms along the way, outline my specific area of enquiry and justify my selection of methodology.

## **Research Aims**

Appropriately, in response to interactions with research participants, the aims of this practice-based research have shifted in emphasis over time. My initial aims were process- and object-oriented, focussing on introducing the concept of a decorated breast prosthesis and exploring the appetite for custom and bespoke designs; finding theoretical support for the proposition that choice and the opportunity to design or customise a prosthesis could contribute positively to the wellbeing of women post-mastectomy, and establishing a methodology for designing or customising a decorated breast prosthesis that involves the wearer in the role of designer or co-designer. However, as I began to interact with research participants and develop some understanding of their experiences, my focus became human-oriented.

First, I expanded my vision, from a purely aesthetic focus, to **adopt a holistic focus which includes physical and experiential aspects of prosthesis-use, as well as aesthetic and psychological.**

Second, as I broadened my focus to include women's varying priorities for the EBP, the value of co-design and speculative design to provide insights and generate ideas became apparent. Consequently, the intention to **examine the value to product innovation of various collaborative design methods** crystallised.

Third, finding theoretical support for the relationship between the aesthetics of prosthetics and wearer-wellbeing was de-prioritised, making way for practical exploration of what it means to **work empathically and use emotional data to inform design and dissemination**.

Key objectives of the practice-based research were, initially, to **create a range of concept models that communicated the idea of a decorative prosthesis** and to find a reliable and skin-safe method of transferring imagery onto the polyurethane sleeve of a silicone gel prosthesis. Satisfaction of the first objective led to disruption of the second: women were simply not interested in a decorated surface to a prosthesis they found uncomfortable. I therefore re-focused my objectives to **practically explore how the EBP could be re-imagined in terms of its meaning, and crucially, its structure**.

The key research outcome remained constant: **create guidance for designers and manufacturers to help improve EBPs and women's experience while using them** (see chapter 4: Synthesis).

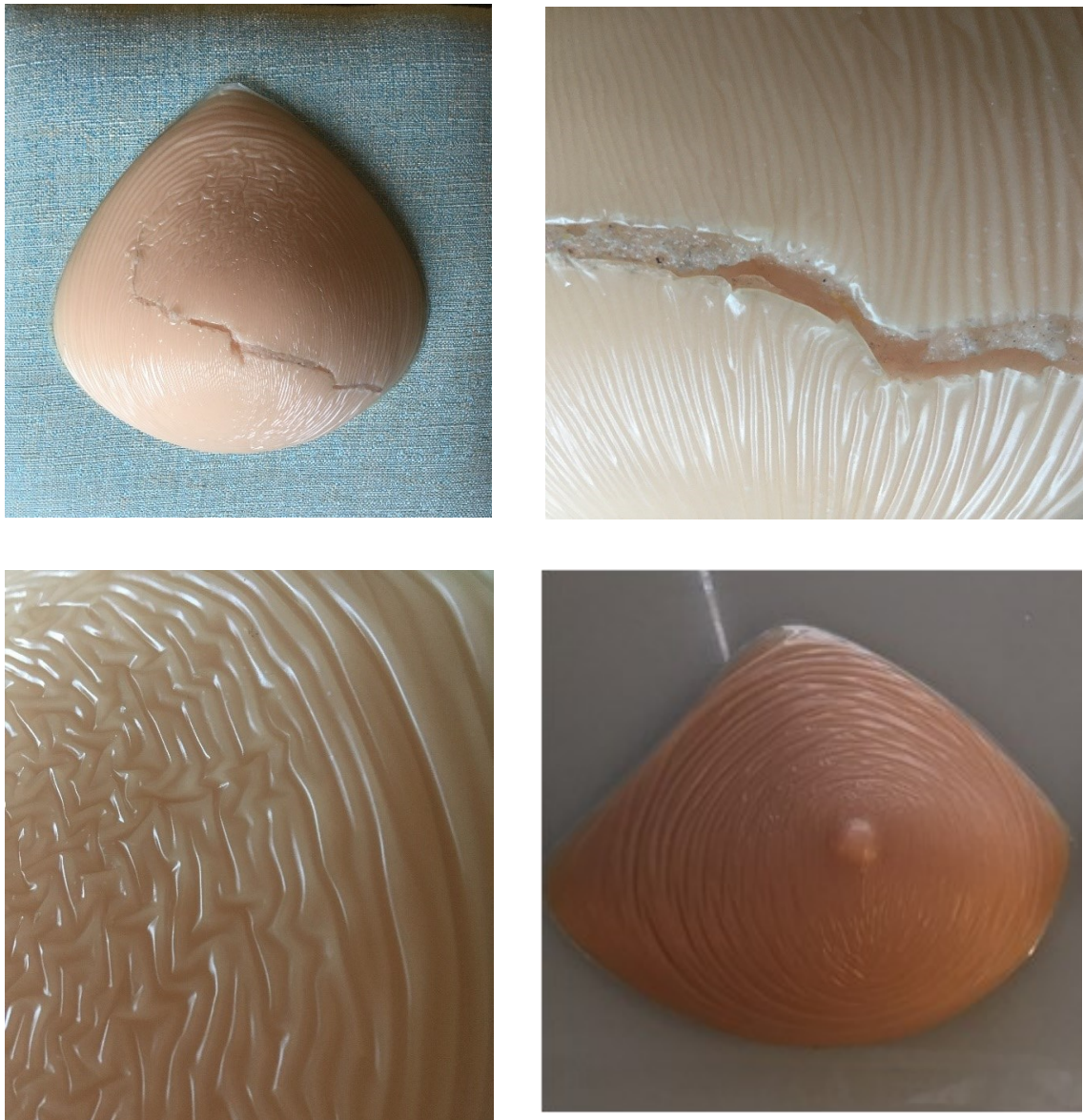
## 1.2 EBP: the product

The current standard external breast prosthesis is designed to approximate a Caucasian skin-tone<sup>1</sup> and some include a small “nub” which imitates a partially erect nipple. The prosthesis does not include an areola and there is no colour change for the nipple. Made from silicone gel and encased in a polyurethane film, the prosthesis is designed to feel like human skin to the touch and move like breast tissue does under pressure. Lighter-weight versions made from foam or filled with polyurethane beads may be worn for exercise or in preference to the heavier versions. They may be worn inside a specialist pocketed bra or may be worn in direct contact with the skin, secured with adhesive pads.

For women in the UK, silicone gel prostheses are available for free on the National Health Service (NHS), and can be replaced free of charge through the same service every 2-5 years. A silicone gel prosthesis will typically last 2 years before it needs replacing. It may last up to 5 years, depending on how much it is worn and how carefully it is handled. Eventually, the polyurethane film that encases the gel will split.

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<sup>1</sup> Leading prosthesis retailers' websites in the UK and USA depict products available in only one to three skin-tone options: always a light brown, sometimes a mid-brown and occasionally, a darker brown. Not only is there minimal representation of women's skin tones in the number of colour variants – for example, as compared with cosmetics – but an informal analysis of product lines found that those designed to blend in with a Caucasian skin tone outweigh those designed for women of colour by at least 9:1.



**Figure 1: Silicone gel prosthesis**

Women may choose to purchase additional or replacement prostheses and typically do so from online specialist retailers. Purchasing additional prostheses, for example for use when swimming, incurs additional costs for the wearer, as the silicone gel prosthesis is neither practical for use in water due its weight nor recommended by retailers due its material composition. Women who ordinarily wear silicone gel prostheses will need to purchase a specialist swimming prosthesis. For those women who have had a bi-lateral mastectomy, the expense is doubled.

Alternatively, if a woman wants a lightweight prosthesis and does not require it to be semi- or highly-realistic, she may opt for a “knitted knocker” breast form, a knitted or crocheted sleeve which contains a soft, removable textile filling. Knitted Knockers are produced free by volunteers and provide women with the choice to select the colour of their breast form.

Prior to the second world war, prostheses were all generally improvised devices, made from fabric and filled with a variety of soft, flexible and removable fillings. Commercially available bust-enhancing products were sold but this was more for the purposes of visual augmentation than physical replacement. The first patent application for a breast prosthesis that makes mention of mastectomy was in 1922 and was submitted by a woman. Pre-war production of prostheses was very much small-scale and done by individuals or small companies of 2 or 3 employees.

(Gardner, 2002)

It was not until after World War II, when company Dow Corning was looking for new applications of silicone that this started to be used in external breast prostheses, and production shifted to a larger-scale: with it, the emphasis from a bespoke fit to a uniform approach, using moulds and set processes (Gardner, 2000). The design and production were largely dominated by men, but in 1976<sup>2</sup>, creator of the Barbie Doll, Ruth Handler, formed a prosthesis company, Nearly Me, borne out of her own personal experiences of breast cancer and inadequate provision, having been told to "stuff her bra with stockings" by her doctor.

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<sup>2</sup> <https://www.theguardian.com/news/2002/apr/29/genderissues>

### 1.3 The wearer and her experiences

Women who have one or both breasts removed and do not opt for immediate reconstruction will usually wear a prosthesis, either temporarily, if having a delayed reconstruction, or permanently if not having further surgery. Initially, a woman will wear a lightweight, soft foam breast form called a “softie” and after around six weeks of healing time, she will be fitted for a heavier silicone gel prosthesis, designed to replicate the weight of the natural breast.

The external breast prosthesis performs no medical function but exists only to restore a feminine form under clothing and in some cases, resultant confidence in the wearer. It is the favoured choice for 90% of Western women after mastectomy (Kubon, 2012) and the only medical option for restoring form available to some, due to age or health complications that prevent further breast surgery.

Fitch *et al.*, 2012, captured women’s experiences of their prosthesis; their complaints are echoed by my participants’ responses, both citing temperature, weight and expense as issues. Looking at manufacturers’ websites, it is clear there have been many technological improvements, but as Fitch *et al.* identify, if breast care nurses are not aware of the current research on newer materials they might not give the best advice. Additionally, hospital budgets mean buyers have limited product choices for purchase and stock. In turn, women have a “sub-standard” prosthesis, or those who have had one for a long time stay with an older model because it is familiar, despite improvements being available (at a price). Where women do pay for the prosthesis themselves, cost is a factor in whether they replace it or not, and cost trumps comfort. (Liang & Xu, 2015)

Frequency of use varies: some women wear an EBP only for “special occasions” or when meeting someone new; others wear a prosthesis when outside the home but in the company of friends and loved ones, will go without; still other women will only remove a prosthesis to clean it or if it needs replacing.

A prosthesis performs both a social and personal role in restoring the appearance of a feminine form. However, the difference in how a woman feels about her body and herself may be at odds with her clothed appearance, a phenomenon which I support with data in section 3.7.3, and for which I propose a corrective design framework, antidotal design, in section 2.6 and section 4.3.2.

In *The Cancer Journals* (1980), Audre Lorde writes of the emphasis by the medical and allied health industries on appearance as the “sum total” of womanhood, where perception is all, but is herself highly critical of attempts to alter appearance, either by surgery or prosthesis, because it denies the physical and psychological reality of the change; furthermore, it renders women’s experiences invisible, thereby removing the potential to provide support and kinship.

Gallagher *et al.* (2006, 2009) identified the importance of the prosthesis for shape, appearance to self, appearance to others, sense of well-being, self-confidence and femininity. Dissatisfaction with weight, comfort and movement of the prosthesis was identified, and cost and travel distance were found to influence the replacement of the prosthesis.

Most women are grateful to be alive (Gallagher *et al.*, 2010); consequently, any



dissatisfaction with the prosthesis is overshadowed. According to Gallagher *et al.*, 2009, there is a lack of scientific literature addressing issues of satisfaction. While the Glaus & Carlson, 2009 quantitative study on satisfaction with prosthesis indicated that women who wore it more were more satisfied than those who wore it less; this should not necessarily be interpreted as causal: if a woman does not like her prosthesis, she may not wear it; it is not proven that the act of wearing increases satisfaction.

However, a wellbeing audit of women who had reconstruction after mastectomy as compared to those who did not found that women who do not have a reconstruction score lower against several wellbeing measures (NHS *et al.*, 2011). This being the case, it seemed necessary that attention should be directed towards how wellbeing might be improved in women who do not choose reconstruction.

With this research, it was my intention to lay a foundation for health psychology scholars to explore whether creative input into the design of a personalised EBP might contribute to wearer wellbeing. An examination of the current attitudes around the aesthetics of EBP by wearers, and the facilitating of creative and co-design activities, were chosen to gain insights into future possibilities for alternative aesthetics of EBP.

Finding a gap in the literature, I consulted prosthetists and turned to first-person accounts, thus resulting in the learning that women respond to the pseudo-realistic aesthetics of the EBP in varying ways. For some, a high degree of realism is important. Some women may feel this strongly enough that they are referred to a

prosthetist, or pay for the service privately, to have a highly detailed bespoke prosthesis designed for them. Most white women will be moderately satisfied with a semi-realistic prosthesis, but some reject the notion that an EBP needs to look realistic:

*“There’s no point in trying to make a false boob look like a boob.”* - Sue

*“If it’s not seen then why does it need to be skin tone?”* - (Bosom Pals workshop participant)

Some women do not place any importance on the appearance of the prosthesis:

*“If a prosthesis was light weight and comfortable and affordable then it can be any combination of colours.”* - Heather

Consideration of aesthetics for a prosthesis that is not publicly visible is irrelevant to some women: “If nobody sees it, what does it matter what it looks like?”. However, this research takes the practices of emotional design, interaction design and user experience, to consider what emotional affordances (Norman, 2004) an EBP could have.

This research explores the emotional journey women navigate, from breast cancer diagnosis, through surgery and beyond into prosthesis use, which provides justification for the human-centred and empathic approaches to design practice.

*“We all laugh about it but deep down I think we want to throw them across the room”*

- Jessica

## 1.4 EBP context

*An EBP is a way of trying to look like everybody else although still feeling different” -*  
Foxy Ladies participant, 1E

The current EBP is a mass-manufactured product, and is, therefore, part of a closed design process excluding wearer-participation. While material improvements have occurred, the aesthetics of the EBP have remained largely unchanged for over 50 years<sup>3</sup>. As Assink, 2006 details, an incremental approach to product development can hamper innovation. If issues of efficiency, profitability and low risk are key business concerns, then designers are unlikely to look too far from their previous work when making new developments. The status quo is supported by minimal research literature indicating that women are dissatisfied with their EBP on grounds of aesthetics.

Innovations in EBP design focus on the use of 3D laser scanning and 3D printing technologies to produce moulds, consistent with process innovations in other areas of prosthetics (Cruz *et al.*, 2020). However, in the area of aesthetics, the EBP contrasts that of prosthetic limbs.

Regardless of the designer or manufacturer, external prosthetic breasts look much the same whoever is producing them. In contrast, there is far more variety currently available to wearers of prosthetic limbs.

Perhaps because prosthetic limb covers can be made of a rigid material, as opposed

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<sup>3</sup> <https://www.amoena.com/uk-en/about-us/amoena-timeline2>

to the soft give of a silicone gel prosthesis, far more variety in appearance is available, and designs can be produced and modified with ease, at speed, and with relative economy, via 3D printing and opensource designs.

Whether the wearer desires a robotic aesthetic<sup>4</sup>, something related to their favourite Disney® character or action superhero,<sup>5</sup> or picks from a wide range of styles and fashion influences,<sup>6</sup> there is choice.

Prices and customer-involvement range from the completely bespoke and artistic by The Alternative Limb Project<sup>7</sup> to the economical, fun and mass-produced, Confetti, “the world’s first mass-produced prosthetic leg” by Furf Design Studio and ID Ethnos<sup>8</sup>.

Bespoke options in terms of sizing, profile and colour matching or surface detail are available for prosthetic breasts, but in terms of a varied aesthetics, silicone gel prostheses remain resolutely realistic. A realistic aesthetic will be important to some wearers, but LaBat *et al.* (2017) found that women perceive skin-toned post-mastectomy products as medicalised. Likewise, Law *et al.* (2016) found that “nude” colouration of scoliosis braces had medical associations and was perceived negatively, whereas co-designing decorative surface designs positively influenced wearer perception.

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<sup>4</sup> <https://3dprintingindustry.com/news/glaze-prosthetics-superhuman-3d-printed-prostheses-amputees-122974/>

<sup>5</sup> <https://openbionics.com/>

<sup>6</sup> <http://unyq.com/en/home-en/>  
<https://alleles.ca/>

<sup>7</sup> <http://www.thealternativelimbproject.com/>

<sup>8</sup> <https://designwanted.com/design/prosthetic-leg-cover-furf-design/>

An approach to re-imagining the aesthetics of EBP is yet to be covered in the literature. This research seeks to highlight the gap in knowledge and practice by outlining approaches which designers and design-researchers can take to advance the field and social discourse and increase the levels of choice which consumers now expect:

*“Back when I had it [a mastectomy] done, beige was fine because that was all you knew. But times have moved on, and people have moved on. It would be nice to have a choice.” – Sue*

Providing more choice in the range of aesthetics of EBP has a psychologically based rationale. Hilhorst (2004), Vainshtein (2012) and Sansoni (2015), all point to the psychological benefit of being able to customise and choose a variety of aesthetics for prosthetics. User-focused prosthetics can be produced in the wearer’s favourite colour, customised by or for the wearer, and used to challenge the social meanings of prosthesis use. Where budget allows, wholly bespoke prostheses can be produced, such as the various limb prostheses worn by “bionic pop artist”, Viktoria Modesta<sup>9</sup>.

Visibility increases social acceptability. Social attitudes towards visible prosthesis-use have shifted over the past century. The social stigma of a prosthesis in the Victorian era began to erode with the increase in numbers of prosthesis users as a result of limb-loss in the World War II (Cauwels, 1986). In the last 20 years, the

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<sup>9</sup> <https://www.youtube.com/watch?v=m1CG2XpkBis> Excellent talk about the Body as Art, by Viktoria Modesta.

representation of prostheses in popular culture<sup>10</sup> has served to further shift the discourse, inverting the narrative from one of limitation to one of enhancement.

*“When you watch the Olympics and people have their blades, or if you watch Strictly - Johnny Peacock has got his prosthesis on show. I think it’s such a good idea because it’s [this attitude of] ‘here’s my disability and I’m proud of it’.” - Becci*

The discourse of prosthetic breasts, however, is one of deficiency, necessitating further surgery or the wearing of a realistic EBP to become whole again (Cromptvoets, 2012).

Rejecting the validity of this notion, examining the literature on expressive prostheses (Hall & Orzada, 2015; Lamb & Kallal, 1992), and emotionally driven limb prostheses (Vlachaki, 2020), and using the guiding principle of *kintsugi*<sup>11</sup>, the researcher asks whether the creative, social and psychological benefit of these prostheses could translate to the EBP.

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<sup>10</sup> The framing of limb prostheses changed in the fashion world in 1998 with Aimee Mullins appearing on Alexander McQueen catwalk and Dazed and Confused cover. In sport, first Oscar Pistorious competed professionally wearing “blade” prosthetics, followed by the branding of the 2012 Paralympians as “Superhumans”. What had been a niche aesthetic was introduced to mass-consciousness in the 2012 Paralympic Games and later, in appearances in Hollywood feature series, *Kingsman*. An indication of the extent to which these aesthetics of prosthetics have now reached the status of being pervasive, can be found in the striking resemblance between Serfaty’s 2010 *Outfeet*, an adaptable below-knee lower limb prosthesis, and Balenciaga’s Fall/Winter 2020 *Toe Sock* and *Heeled Toe*. These footwear with elevated heels, stretchy sock upper and individually splayed toe sockets draw on a distinctly prosthetic aesthetic. The design augments the height of the wearer, provides spring and embodies the concept of prosthesis as extension. See the last image on this website: <https://www.designboom.com/design/aviya-serfaty-prosthetic-leg-for-women/> and contrast it with that of the *Toe Sock* on the Balenciaga website.

<sup>11</sup> The Japanese art of *kintsugi* turns the repair of broken ceramics into a form of enhancement. The repair is not hidden, does not devalue the object but instead becomes part of the object’s story and a way of cherishing the object and acknowledging (and even increasing) its value.

This research has consequently sought to prototype the design of an expressive prosthesis<sup>12</sup>, and identify a number of desirable product qualities, with the aim of inspiring designers to diversify their designs, thus creating a context for increased wearer satisfaction and new social meanings for the EBP.

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<sup>12</sup> The term expressive prosthesis is used here to describe a prosthesis which visually encompasses concepts pertinent to the wearer's identity, (Hall & Orzada 2015). In my practice, I add to their definition that personally meaningful text and imagery can form part of an EBP's expressiveness.



## 1.5 Research enquiry

The scope of the research is confined to female participants who have had at least one mastectomy due to having breast cancer, and now wear an external breast prosthesis<sup>13</sup>. I explored these women's physical, social and emotional experiences of prosthesis to understand what works well and what could be better. I have predominantly focussed on women in South West England who attended one of three regional independent breast cancer support groups but also recruited participants and steering committee members from UK regions, and English-speaking countries: New Zealand, Australia, and the USA.

My research questions have evolved as the research has progressed, in line with Grounded Theory. Initial interest centred on whether a realistic aesthetic was universally desirable by wearers and whether being involved in the design, customisation or personalisation of an EBP could benefit the wearer's wellbeing. The enquiry shifted its emphasis to focus on understanding and reflecting counter-normative narratives of women's experiences of owning and wearing an external breast prosthesis; to understand – if given the choice - which attributes (both practical and fantastical) women would choose for their prosthesis, and to consider the role of creative and participatory practice in generating alternative and transformational possibilities.

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<sup>13</sup> The research focus excludes the experiences of cross-dressing men, transgender women, women who have had a lumpectomy and women who have had a prophylactic mastectomy (preventative) or who wear a prosthesis for other reasons, such as a congenital breast conditions where breast tissue growth is limited or absent.

The focus of the enquiry can be summarised in the following research questions:

**1. How do the prevalent aesthetics of external breast prostheses shape the physical and psychological experience of the wearer?**

**2. How might the EBP be re-imagined?**

The first question is intended to provide an empathic context for the designer-researcher to explore creatively the second question through practice-based research.

## 1.6 Methodology

While this research aimed to expose hidden stories, there are further hidden stories not collected because my access was limited to participants who were members of physical or online groups, volunteers whose responsibility it was to talk to others about their experiences, or women who had educated, engaged and tech-literate advocates with whom I could connect. For those women who are not part of a group or have no one to advocate for them, these stories remain unknown and truly hidden.

My own approach to research design was justified by the desire to capture rich data and insights into women's experiences that would both inform my understanding and therefore improve my ability to communicate any new knowledge, and inform and permeate my design and making practice. As such, a smaller sample size would yield varied themes yet still provide a base for comparative analysis. Additionally, keeping numbers small, enabled me to form more productive interactions with research participants (see appendix A for further detail).

It was appropriate to use multiple methods because my focus was more than just a design issue or human function issue. Aesthetics and how they influence the wearer's experience relate to materials, human psychology, cultural meanings, body politics and much more. Adopting a multimethod qualitative approach allowed me to explore the subject from a range of perspectives and angles and gain a rich understanding with which I could generate a range of critical, discursive and speculative outputs, each informing the other. A qualitative approach with open questions and prompt-based activities allowed participants the freedom to generate

their own responses using their own choice of words, something that would inform later language-use within activities, but also helped to remove researcher-bias in the research design.

To further address the issue of bias, I adopted aspects of the Grounded Theory method to enable me to develop a theory regarding the aesthetics of external prosthetic breasts that was grounded in research data (see section 4.3.1).

Tim Plowman in *Ethnography in Critical Design Practice*, in *Design Research* states that "...the majority of designed artifacts are planned, prototyped and produced without the benefit of primary, ethnographic research on intended audiences and the context of use." In contrast, I have drawn on insights using design ethnography techniques and reflective activities to establish an empathic foundation for design work. Additionally, cultural probes (Gaver, Dunne & Pacenti, 1999), (Sanders & Stappers, 2014), interviews and "contextmapping" (Visser *et al.*, 2005), provided insights into wearer experience, which according to Sanders and as I believe, encompasses "past, present and future".

As one of the motivations for the research was to affect social change, I took cues from action-oriented research and participatory design to consider the way in which I conducted research activities, aiming to be mindful of power dynamics (see appendix B for a list of choices I made that evidence an underlying feminist and inclusive philosophy). To ensure that any knowledge created could be applied, I chose to deliver student workshops, curate a public exhibition and write a set of design guidelines and designer's creative prompts as acts of dissemination. Furthermore,

the act of participatory design research itself was intended as consciousness raising and the practice element can be understood broadly as discursive design.

The use of discursive design (Tharp & Tharp, 2019) was an essential part of evoking reactions in participants that would provide research insights and ensure that stakeholders would consider how the EBP, both functionally and culturally, could be transformed.

One strand of discursive design is critical design (Tharp & Tharp, 2019). Taking a critical stance of the status quo and standard design practices meant that both participatory or co-design and critical design were appropriate forms to adopt to challenge the dominant aesthetic of the EBP. Because there was no commercial precedent for a non-realistic EBP, I looked to speculative design methods (Dunne, 2013) to inform my own design practice and to facilitate participants in imagining future prosthetics.

The combination of understanding the social and emotional aspects of women's experiences with experimental, critical and speculative design practices and an analysis of the cultural context in which EBPs are made and used, succeeded in creating a holistic approach to considering future possibilities for the EBP.

Challenging the status quo of EBP design called for new design methods or new combinations of existing methods. Opposing the standard necessitated adopting alternative design methodologies to those used within industry. Drawing inspiration from a variety of design and research methodologies, methods and techniques, I

have created my own approach to collective re-imagining. This approach is atypical of how medical products are designed: in a medical context, the user is the subject, not the design/research partner. The more the user is involved, the more likely their emotional and psychological concerns will be represented in the design. The less the user is involved, the more likely focus will remain solely on the functional aspects of the product.

*We have no systematic way of developing a social needs inventory to stimulate the invention of beneficial new products." - (Margolin, 2016)*

After gaining initial insights into wearer experiences through interview and written accounts, the first step was to consider how the design of the EBP could better meet the needs of the women who wear them. Rather than make assumptions about what was wanted or what was practical to produce, I set out to build a grounded theory and then apply this to the creation of a prototype EBP. Using principles from established design practices, including participatory design and human-centred-design, I developed a methodology that enabled me to explore the potential affordances, meanings and aesthetics of an alternative EBP product, which situates the work within the field of emotional design, or “design and emotion”, as categorised by Sanders & Stappers (2008).

In addition to established practices, I tentatively propose two approaches: grounded design and antidotal design. Antidotal design is a proposed framework for addressing emotional trauma. It is a process facilitated by a designer, potentially in partnership with a psychologist or psychotherapist, working with a client who would

like to experience some form of change in attitude or behaviour. Encapsulating theories of behavioural change, positive reinforcement and the principles of gestalt therapy, antidotal design provides a visual reminder of a desirable concept and provides the mechanism with which to deliver new messaging, according to client need. To fully flesh out the framework and put it to the test, specialist collaborators and a variety of use cases are required.

Grounded design is a concept currently only applied to an information systems (IS) context (Stevens *et al.*, 2018) but could be useful for design-researchers as a means to reflect upon their values and approach. The term as I use it is intended to follow the ethos of classic grounded theory (Glasser & Straus, 1967), where the researcher arrives at a theory based on minimal prior knowledge of the literature and adopting an iterative process of data collection and analysis. The resulting theory is grounded in the data, rather than confirming or disproving a researcher's initial hypotheses.

Grounded design removes the designer's agenda and preconceptions, allowing user data and designer-researcher analysis to inform the direction of the design process. The resulting design outcome is grounded in the data and in generative activity by both researcher and participants, rather than delivering to a specified brief or based on a designer's original idea.

I have selected and created methodologies that provide a variety of ways of allowing women to generate, express and communicate ideas and priorities in relation to the EBP, as well as provide wide-ranging insights into needs and visual preferences that would inspire my own making practice for the critical design objects. At the conclusion of the research project, I shared design guidelines with participants for

their feedback for the purposes of “member checking”. While not subscribing to Sanders’ definition of Participatory Design, the process I established was nonetheless collaborative and participatory, and the knowledge generated would not be possible were I to have worked alone.



## 1.7 Thesis overview

As practice-based research, the written component forms only part of the thesis. Accounts of practice and methodology are described herein and supplemented by visual documentation in the accompanying digital portfolio. The written component of the thesis is comprised of five chapters:

The first chapter introduces the research aims, topic, scope, methodology and positioning within the wider research context. The chapter introduces necessary personal, industrial and cultural context for understanding the EBP as it currently is experienced and considering what it could become in future.

The second chapter introduces aspects of the practitioner-researcher's role in designing and executing research with participants. Addressing matters of ethics, bias, collaboration and use of methods, the chapter provides insight into the approach to practice-based research. A framework for working with design and emotion is proposed, and an overview of the evolution of practice is provided which serves as an introduction to the more detailed description of practice elements which follows in the next chapter.

The third chapter provides an account of seven practice-based research elements, a justification of decisions made and a summary analysis of what I learned and where relevant, where I applied this knowledge. The chapter can be understood as a combined methods and results chapter.

The fourth chapter synthesises the learning from the multi-method research and

practice into six guides and summaries which researchers and design practitioners can immediately apply.

The fifth chapter concludes the thesis with a summary of learning, proposed contributions to knowledge and recommendations for further research and practice. Concluding remarks and a call to action complete the written thesis.

## **CHAPTER 2: METHODS & AN INTRODUCTION TO PRACTICE**

### 2.1 Chapter Introduction

In this chapter I introduce the issues of researcher ethics and bias, and ownership of research outcomes. I describe and justify my chosen methods and provide an overview of how the practice evolved. I introduce the emotional component to my work which accompanies the visual. This chapter enables a more insightful reading of the practices related in chapter 3.

## 2.2 Notes on Ethical practice

Conducting research with participants demands ethical practice. The project proposal was subject to a rigorous ethical approval process and was approved by the University of Plymouth's Research Ethics Committee prior to my initiating participant recruitment. I recruited outside of NHS-run services and was therefore not required to seek NHS ethical approval. Additionally, I formed an online steering group of stakeholders who could feedback on the research design.

I have observed participants' directions on whether they consent to disclose personally identifiable data or appear in images. Names, faces and other personally identifiable data which appear in the thesis, appendices or digital portfolio, do so with permission. Participant data is mostly anonymised, but on occasion, first names are used to humanise<sup>14</sup> participants. A sample informed consent form can be found in appendix C.

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<sup>14</sup> All my participants are human participants and of course do not require any humanising. However, it is important that the reader be reminded of this by the use of names as opposed to participant ID numbers, from time to time.

## 2.3 Notes on designer-researcher bias

As a reflective researcher and practitioner, it is necessary to consider what bias I brought to the research. As a woman with breasts, I share some commonality with research participants. However, as an outsider in terms of experiencing breast cancer or wearing an EBP, I was therefore reliant on empathy and a partial understanding of the significance of losing a breast, plus my own visceral reactions to the appearance and materiality of the EBP. My responses will have been affected by how wearers represented their experiences, and my interpretations of these accounts will have been influenced by my arts education, love of colour and often individualist outlook.

I have acted from the position of someone who considers aesthetics to be more than superficial; believing how something looks determines how it will be perceived and used and whether it will be enjoyed. I embarked on this research with a concept I believed could be commercialised, but participant interaction soon dispensed with my assumptions<sup>15</sup>. The practice was very much a discipline of “unlearning myself” and opening myself up to allow others’ perspectives to inform my research and design direction: a constant negotiation between being critical, accepting and curious.

I do not subscribe to the positivist position of researcher-neutrality, but neither have I sought to actively make myself part of the research. While I maintained a reflexive

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<sup>15</sup> The principal assumption I refer to here was that an EBP with a decorated surface would be appealing to wearers, especially if they were involved in its design.

journal to highlight potential biases at play, my intention in articulating ideas was to foreground women's voices and act firmly as auxiliary.

## 2.4 Notes on collaboration

In conducting practice-based research, I consider my role to be that of designer-researcher, encompassing sub-roles of learner, facilitator, synthesiser, co-creator, curator and provocateur.

My intention has been to create conditions that elicit stories, discussion and ideas, and to handle these outputs sensitively, in the service of participants, to advance thinking about EBP design. While I have applied my skills to devise and frame activities, and analyse, synthesise and communicate the resulting information, the endeavour of re-imagining the EBP would not be possible without the contributions of a great many people. As such, the ownership of the knowledge and ideas arising in this project is shared. This being the case, a co-design approach may be less desirable commercially due to the potential for ill-defined boundaries around intellectual property. Equally, with a clear commercial agenda, potential participants may anticipate exploitation, deterring participation. Creating a collaborative design research context, driven by a desire to understand and explore, has proven fruitful for generating new possibilities.

## 2.5 Methods

In considering which methods to use within this research, among them I consulted the method cards of human-centred design practice, IDEO, and looked at Gaver, Dunne & Pacenti's (1999) use of cultural probes. I selected a range of methods that would elicit stories, visual or written data, or would stimulate the imagination during generative activities. Some of these methods were used on multiple occasions and so are outlined once here rather than in each instance they were used in the account of practice in chapter 3.

### **Postcards and worksheets (Questionnaires)**

Following the practice of Gaver *et al.*, single questions were handwritten on the back of postcards as an informal format of a questionnaire. This format was successful for several reasons: one, because the space available required the participant to be succinct; two, because it broke up the questionnaire into individual questions so as not to be overwhelming, and three, because providing imagery on the front of the postcard, the personalisation of a handwritten message (in the person's favourite colour) and the potential positive associations with sending a postcard from a relaxing holiday rather than negative emotions that might be associated with form-filling, all combined to help the participant relax and share something personal and honest. The culture of letter writing is reciprocal, and (like with Gaver *et al.*) participants were of an age where this practice would likely have been a part of their life into adulthood.

Worksheets used within workshops were a second alternative format for a



questionnaire. Again, limited space required participants to be succinct, and using the same format to question each participant allowed the potential for the researcher to perform comparative analysis.

### **Object and Photo Elicitation**

Object elicitation works on the same principle as photo elicitation (Harper, 2002), a technique used by sociologists to aid semi-structured interviews. The object or image provides a focal point for conversation. If responses are required about a specific concept, then having a visual representation for the participant to see and touch can help ensure that the participant is both attentionally present and discussing the subject the researcher intends.

### **Journaling and Photography**

As a contrast to supplying stimuli to participants, I provided the opportunity for them to supply their own self-generated imagery by providing them with a disposable camera and a notebook. Participants could create a journal and document aspects of their experience or they could use the camera to capture anything that was important or visually appealing to them. This provided me with rich insight into visual preferences and mindset.

Journaling and photography are particularly effective in that they give much more authorship and agency to the participant. While some guidelines may be provided, the participant can interpret them as she pleases and determine the frequency, duration and level of detail she supplies. This disrupts the power imbalance present in some researcher-participant relationships where the control lies

with the interviewer who is able to lead the direction of conversation to fulfil their own agenda. It was important to me that this not be the case in my own practice.

## **Collage**

Similar in intention to journaling and photography, using collage as a method to generate imagery provided participants who were less comfortable with drawing, writing or photography with a means to communicate concepts that matched their ability level. Assembling imagery from existing sources allowed participants to create a mood board which provided the designer-researcher with visual stimuli and material for analysis.

## **Think Aloud**

Think Aloud is technique that has aspects in common with object elicitation. It is often used in user research where a person verbalises every thought, without censorship, as it comes to mind while they are conducting a task. In my case, I asked students to handle a breast prosthesis and breast prosthesis packaging so that I could hear what they observed and understood about these objects rather than me imparting my opinions.

Think Aloud is a useful exercise to capture insightful adjectives and assess whether perceptions match the intended qualities of a product. It can highlight issues that a user faces when trying to use a product and can organically capture suggestions for improvement, as they occur to the user.

I used Think Aloud at a late stage in the research process but in future would use it

at the start to produce a list of words that would provide stimuli for follow-on creative activity, as well as produce words that could later be used on prompt cards to help capture clear insight into product traits that are considered desirable and non-desirable within a card sorting<sup>16</sup> exercise.

### **Prompt cards and Scenarios**

Inspired by creative exercises: De Bono (2007, 1990) Monopoly® chance cards, Brian Eno's Oblique Strategies and Dadaist games, I used the concept of a wild card or prompt cards to add elements of chance and the unexpected into participants' creative process, diverting people's thought trajectory. Additionally, I invited participants to consider different scenarios (Dunne, 2013) and how these might change what they required from an EBP.

When people are used to thinking of an object being used in a particular scenario they will visualise the object as it is. However, if we want them to think of the object as having different qualities and appearance then we can encourage them to consider how it might look and function in other scenarios. By making the scenarios extreme, humorous and unlikely, it can uncover ideas, unconscious wishes or ideas that would not be accessible if asked the same question directly. These techniques, while appearing to be superficial and fun were a subtle means of gaining access to people's unacknowledged desires in the present.

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<sup>16</sup> Card sorting is a method which can be used to help the participant create an understanding of their preferences. The researcher provides each participant with an identical pack of cards. The participant sorts the cards according to categories, typically arranged to indicate a priority order, preferences or strength of feeling. The results can be captured photographically and inputted later if a manual process is most appropriate, or the same concept can be achieved in a digital environment.

The above represent some of my most used methods which I adapted over time as my research focus narrowed.

## 2.6 Towards antidotal design

I consider my practice to be more than visual; a form of holistic design or design for wellbeing. Alongside the visible work of exploring alternative aesthetics and form for the EBP, by reflecting on women's experiences I have identified the potential to use design to rearticulate the symbolic meaning of the EBP, and more generally, consider how this might be applied to address issues of emotional trauma.

I have formulated a model of antidotal design, (see 4.3.2 for a visual model and proposed usage guide), the intentions of which is to combine beauty, function and personal story with the goal of effecting a positive transformation of mindset and meaning, personal and social.

I offer the re-imagining of the EBP as the first sample of antidotal design:

For women who are left feeling broken after mastectomy, I propose the use of design as (a partial) antidote - "antidotal design" - which in this practice-based research serves to reconnect the woman with her self. As with the Japanese art of *kintsugi* (repairing broken ceramics with gold joinery), I am fascinated by the restorative potential of beautiful designs, worn on or next to the post-mastectomy body, to change the affect of the daily rituals of dressing and undressing, whether performed socially or alone.

Instead of a site of loss, requiring replacement with artifice and silence to hide or even deny the pain of the cancer journey, the EBP can become a site of creation and

transformation, which nonetheless acknowledges the same pain of the cancer journey but recognises, too, the potential for beauty and preciousness to arise from the broken places; and, in time, a renewed strength to move on.

Combining an object that does not belong to the body, but which is conceived by the mind that does, with a body that is a current site of painful experiences and broken connections to (happier) ideas of self, could begin a *gestaltian*<sup>17</sup> process which integrates these broken pieces into an altered and renewed self. The act is one of hope which combines an uncompromising willingness to confront the truth with the impetus to move beyond appearances and reconnect to the authentic self.

*"If nobody sees it what does it matter what it looks like?" I see it, I matter.*

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<sup>17</sup> This term alludes to the principle of *gestalt* or integrated whole, which originates in a psychological theory of human perception and which has been developed into a form of therapy: *gestalt* therapy, a holistic approach designed to help clients effect positive change.

## 2.7 Evolution of practice

Designs for an alternative EBP evolved in relation to learning through making, exposure to the experiences and desires shared by women who wear an EBP and under the influence of visual research conducted alongside and in response to the above.

Additionally, as 3D printing was the primary method for realising concept models, the prevalent aesthetics within 3D printing and the accompanying software, as well as the work of artistic innovators in 3D printing, such as Neri Oxman, also influenced design development and created an understanding of available additive manufacturing technologies.

Speculative and critical design (Dunne, 2013), discursive design (Tharp & Tharp, 2019), human-centred design (IDEO<sup>18</sup>) and emotional design (Norman, 2004), (Chapman, 2015), all informed the intentions behind the work and the design methodology. However, as the design concept for an alternative EBP originated with someone else, in that same spirit, I kept responding to the ideas, challenges and desires of others rather than my own preferences to inform the design development, and my practice became a collaborative or co-design process.

This research was intended to be discursive, to prompt and provoke discussion, enabling learning to occur for both the designer-researcher, the wearer, and in time,

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<sup>18</sup> <https://www.ideo.com/eu>

the wider public and prosthetics industry.

I began with a more speculative approach, intending to provoke the imagination, break taboos and help people dream.

As someone who values independence and originality, I initially gave undue weight to the appeal of a customised or personalised prosthesis. I imagined that any barrier to acceptance of the concept would be primarily due to its unfamiliarity.

I did not account for the strength of desire for “normality”. It did not occur to me that women might want the prosthesis to look like part of their body. From my observations and the accounts of Sue Jackman, it seemed clear that an EBP could not be viewed as a fully realistic body part. I could clearly imagine an obviously artificial aesthetic might provide an “honest” alternative, since true realism and restoration were impossible. But just because it is not possible to restore the body to its pre-surgery form does not mean that the desire for it has gone. The labels exercise captured the intense grief and sense of loss after mastectomy and desire to return to “normal”.

*“I’m 39 years old. I’m not 89, and I want something that looks pretty. I still want to feel feminine whether I’ve got two breasts, one breast or none at all.” – Kirsty*

One of the strongest feelings from early conversations was the desire to feel feminine and sexy: a feeling lost along with mastectomy for some women, and not helped by the aesthetics of prosthetics, post-surgery lingerie, the difficulty of accessing these items, or their placement within retail outlets.



To address these needs, I conducted visual research on textile embellishments and lingerie aesthetics to inform my next concept models, thus seeking a degree of realism related to lingerie rather than to the breast - which I anticipated might be acceptable.

Another assumption that was shattered by talking to some women was that women would care what their EBP looked like. The view “What does it matter what it looks like if nobody sees it?” was shocking and surprising. I knew not only must I accept that my perspective might fundamentally be flawed, but also that I needed to adapt the activities and visual communication to communicate the emotional or psychological benefit of having a beautiful or personally meaningful EBP to see if this made any difference to the sceptical. I wanted to communicate that even if the prosthesis were only seen by themselves, it would be beneficial for self-esteem if it looked appealing.

My next assumption was about luxury designer EBP, whereby taking the status symbol of a recognisable print or logo, or the smug appreciation of wearing a designer-associated item that no one else knew about, the wearer could derive some pleasure and affirm her self-identity as a fashionable, stylish woman. Apart from some interest in a Cath Kidston print, this idea was roundly rejected as distasteful and undesirable.

Whether this would be all women’s reaction or just those I spoke to is still unanswered, and for a younger or more metropolitan group, perhaps there

would be interest, although for that demographic it is the norm for breast reconstruction and so perhaps there simply is not a market.

Designing for, with, and in response to the women in this project was a journey from different positions, landing at a single point. From my starting position, I hoped to move women towards me, accepting the idea that an EBP could look different, have a different meaning and be positively regarded, not for its realism, but because of the emotional role it played. From the starting position of the research participants, they wanted to be heard. Their feelings had thus far been unrepresented by manufacturers, leading many to make their own solutions, not wear their prosthesis, or suffer in silence.

I moved towards participants by understanding they wanted to be comfortable first, and only then would they love to feel beautiful, feminine and sexy, meaning I had to broaden my scope beyond the visual to include the structural. Some participants moved towards me by accepting that an EBP could look other than anatomical and that this opened the possibility for creative expression, experimentation and new meanings.

In this way, we came to meet in the middle with the idea of lace, something that was archetypically feminine, often used on sexy garments, and which was adaptable enough to incorporate text or imagery that could reflect the individual to make it personal.

Because the lace-like objects I made received the most positive response, I worked thereon with the idea of incorporating the design within the structure of the EBP

rather than having the design on the surface (as I had first imagined) or embedding the design below a clear, soft layer (as I had later imagined).

### **1 SURFACE DESIGN**



### **2 SUB-SURFACE DESIGN**



### **3 INTEGRAL/STRUCTURAL DESIGN**

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The custom designs that research participants created went on to inform the design of exhibition objects, showcasing ten different possibilities of what an EBP could become (see appendix D). In this setting, the focus was discursive; the point was not to create a finished wearable product but to expand the sense of possibility within the mind of the viewer and provoke thought about how things could be different. By rephrasing the statements made in the exhibition, I have created a set of questions for EBP designers that could provoke many varied design responses. (see section 4.3.4).

With the combination of co-design (to include user voices), speculative design (to explore possibilities) and discursive/critical design (to challenge the status quo), I have developed and communicated several speculative possibilities for both aesthetics and meaning which have hitherto been unrepresented in commercial products.

## 2.8 Chapter Conclusion

This chapter outlined my approach to practice as a responsible and responsive researcher and practitioner, described some of the methods I used to inform theory and practice and that would be useful to others undertaking similar work, and introduced a proposed framework for antidotal design as a way of approaching the emotionally laden content of the work. The chapter concludes with an overview of how and why the practice evolved, acting as an introduction to the more detailed account of practice which follows in chapter 3.

## **CHAPTER 3: PRACTICE & LEARNINGS**

### 3.1 Chapter Introduction

This chapter outlines seven elements of my practice-based research, providing a brief description of each, along with a summary of methodology and methods used and the rationale for their selection. I provide a summary of what I learned, an appraisal of success, limitations and where relevant, indicate how this element informed other areas of practice.

Activities chosen fulfilled multiple research aims as part of an emergent and iterative process - as described in section 1.6 - and, consequently, are complex to describe. For clarity and brevity, therefore, I have chosen to set out the seven elements of my practice below, as if they were performed discretely.

## 3.2 Making

### 3.2.1 Making discursive objects and images for elicitation

Photo elicitation cards and speculative designer EBP visualisations were a set of A5 cards containing a range of images for use with prosthesis-wearers to aid discussion and help communicate the concept of a customised, personalised, bespoke or designer collaboration surface design for the prosthesis.

The intention with these images was to stimulate conversation, highlight the inequality between limb and breast prosthesis provision, normalise the concept of a decorated prosthesis by drawing parallels to tattoos and gauge response to the idea that a designer collaboration might change the way women feel about the prosthesis by turning it into a thing of value.

By providing imagery of equivalencies (mastectomy tattoos and limb prostheses) as well as visualisations of what a decorative or designer prosthesis might look like, I provided a visual aid without having to have solved how to physically produce the prosthesis. Presenting socially acceptable visual equivalencies, I hoped to draw a conceptual parallel that would make the idea of a decorative EBP more acceptable. As part of the visualisations, I created some speculative artwork for designer collaborations, imagining what famous fashion logos and iconic surface patterns might look like when transferred onto an EBP. Visualisations provided a way to explore the concept verbally with participants and had there been interest then I could have approached copyright holders in due course to explore licensing.

## **Learnings**

I did not spend much time discussing this concept with the participant group (CanCope) as the group's broad consensus was that a customised EBP was for younger women and or people who wanted to make a statement about their mastectomy. The group talked about the idea of wearing expressive prostheses under sheer clothing so that they could be seen. This comment was interesting to me as even though this group did not feel the concept was for them, they could recognise its value to others, and they identified that by making the prosthesis visible, it might provoke conversation and help people think about the body in a different way.

Photo and object elicitation both proved successful methods for gaining insights into participants' beliefs about themselves, others and the wider culture. Participants were distracted by the surface texture of prototype objects, despite it being explained that these were models and not intended to be worn. I would recommend that designers or researchers conducting similar user research consider using 2D visualisations alongside a representative textured material until such time as it is possible to bring two representative elements together. I learned the concept of "looks like", "feels like" and "works like" prototyping on the Design Council Spark 2018 mentorship programme, but at the time of preparing these objects, I was new to prototyping and unaware that I could use or create multiple elements to build a better sensory experience for the user.

### 3.2.2 Making as product development

Making as product development began as a joint activity with making discursive objects. At this early stage, the focus was on pure experimentation and visualising and trialling concepts in 3D, by whatever means.

Clear forms were the first area of practical exploration. Taking inspiration from swimming prostheses which are clear and either colourless or light blue, I explored the effect of embedding something within a clear substance. I first began with jelly for expediency before moving on to working with resin. Preparatory work involved 3D scanning, photogrammetry, 3D printing a breast form, casting and mould making, providing a range of plaster and rubber positives and plastic, rubber and plaster negatives or moulds. While I could have continued exploring embedding objects within a translucent material, it became clear from participant feedback that this would not deal with the issues of weight and temperature control that were a priority.

Once I had a digital 3D model of a breast form this allowed me to experiment with producing a range of opaque forms. I 3D printed in plastic, 3D printed a patterned surface, tried hydrographics using existing films and created my own hydrographic films. Additionally, as a simpler alternative, I made some fabric covers which could either be stuffed with filling or be used to cover the standard EBP.

The smooth finish of the hydrographic film was appealing to some participants, but it did not address the issue of breathability, and as a practical method of image transfer onto a silicone gel prosthesis, it would not have been appropriate.



Hydrography provided an effective way of producing concept models and would be suitable for plastic limb prostheses, for example, but would not be suitable for the malleable surface of an EBP. With access to the right industrial equipment, imagery could easily be printed onto polyurethane film that currently encases silicone gel in the standard prosthesis. Indeed, one of the leading prosthesis manufacturers has now created a “fashion prosthesis” which has a decorated back to the prosthesis which matches the fabric print of a bra they also produce. While it would not have been too much of a stretch to explore skin-safe printing inks and industrial image transfer methods, persisting with a surface decoration when participants had been vocal about issues of comfort would have been to ignore valuable information.

Following discussion about the parallels between prosthesis and lingerie, and the need for femininity and prettiness, I intended to create a broderie anglaise design. This then led to general visual research for cut out shapes and items with openings or textile-inspired detailing in them. The revelation within this was that pattern could be integral rather than surface.

I produced a framework breast form using a voronoi<sup>19</sup> architecture, to approximate a lace design. I then experimented with overlaying the voronoi with text and could have continued with various imagery. The voronoi was computer generated so I thought it important to also create my own artwork using a repeat pattern.

I started this process with a shell form that communicated the concept of a decorative breast prosthesis but without it being solid or having an internal structure.

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<sup>19</sup> Voronoi is a mathematical calculation for creating simple shapes. It produces an organic, cellular effect.

When this was well-received, I began exploring how to develop an internal structure. I started with columns and then tried digitally assembling a lattice, but ultimately the model needed a more complex and multi-directional internal architecture to allow the EBP to move in all the directions and respond to pressure in the way a breast would (i.e., with variable density). The extent of technical development work required felt tangential from the human-centred aspects of the project, so advancing this aspect became professional enquiry, while my academic focus remained on the discursive and methodological elements of the project.

## **Learnings**

One of the key learnings for this research project was that an EBP need not be solid. This one insight fundamentally disrupts assumptions about the aesthetics of EBP. By having an open structured breast form, the potential for temperature regulation is introduced, as well as the introduction of integral patterns which provide a decorative appearance and could potentially be varied for customisable designs.

While 3D printing provided a means to fabricate prototypes, conversation with an innovative software for 3D printing company revealed that 3D printing as a means of producing wearable EBP products in a range of sizes and colours is not yet viable.

The expense and limitations of using the current state of technology means that for now, the aesthetics of open-structured prosthetics will be limited to designs that can be produced by more conventional manufacturing methods. However, I remain hopeful that with a confluence of material and technology advances, together with existing computer-aided generative design capabilities, that beautiful and impossible-

to-create-any-other-way designs will one day be available for women to customise, wear and enjoy.

### 3.2.3 Making discursive/critical objects for exhibition

Making discursive and critical objects for exhibition is covered in section 3.7.2 where I describe the process of immersing myself in multiple forms of participant data to inform the design of critical exhibition objects.

Creating multiple objects that could communicate concepts and could be displayed securely was a time-consuming process where I used reverse engineering to iterate a design solution for fixing the models to the wall, which pushed my digital 3D modelling skills to a new level

#### **Learnings**

In making for exhibition rather than to elicit thinking and conversation in a closed, research environment, or in prototyping for wearable product development, there are different considerations. As exhibition objects, I could select materials that would not be practical to wear, such as porcelain and glass, and use the poetic associations of preciousness and fragility to add a layer of meaning to some of the objects on display. The novelty of materials and design made for arresting imagery that could be circulated to promote the exhibition.

Setting creative briefs for student designers to respond to and produce some of the exhibition objects, was a way of extending the conversation about EBP design and production as well as considering the qualities necessary in an exhibition object versus a functional product. This was therefore useful experiential learning for me and my collaborators.

### 3.2.4 Collaborative making as dissemination (co-producing/designing with students)

As mentioned in 3.2.3, collaborative making can be a form of dissemination. By involving students in a design process, this necessarily required multiple conversations, joint ideating and problem-solving as well as the opportunity to deliver insights into my empathic co-design methodology and share learnings from my research.

For those students who participated in co-producing exhibition objects and who also attended a workshop and feedback session with me, it created a deeper connection to the research and emotional and intellectual investment in its contents as well as introducing new methods they could apply for their own subsequent practices and providing the opportunity for us all to consider on our ways of working and consider the ways in which introducing a co-design approach to a sector that is not used to it might be handled.<sup>20</sup>

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<sup>20</sup> (Sadly, we did not solve that one!)

### 3.3 Interviews

I interviewed four young women linked with the charity Coppafeel, Bridget, a middle-aged woman from support group Bosom Pals, Sue Jackman (who inspired the project concept) and a range of practitioners: speculative designer Agi Haines whose focus is the design of the human body, international textile and surface-designer Paul Singleton, bespoke prosthesis designer Sophie Oliveira de Barata (The Alternative Limb Project), a chiropractic neurologist who had treated women after mastectomy and a breast cancer care nurse with 30 years' experience.

The intention of initial interviewing was to follow up on themes raised at the breast cancer support group meetings I had attended to introduce the research. Early interviews with women who had had a mastectomy were intended to provide more in-depth insights which would inform research design and provide a means of comparative analysis of experiences. Interviewing practitioners was intended to guide how I framed and understood the creative practice and provide outsider counterpoints to participant's experiences to round out my frames of reference.

Later interviews followed the grounded theory principle of theoretical sampling, using findings from a first analysis, to determine the next sample of participants in order to focus in on that line of enquiry.

Interviews were semi-structured and lasted between 30 and 60 minutes.

Interviewees were provided with questions in advance and signed a consent form for me to use interview contents. The format of the interview was structured flexibly enough to allow the interviewee to raise matters of interest and for the interviewer to

respond while still managing the agreed time frame. A sample protocol and selective transcript/interview summary can be found in appendices E and F.

Semi-structured interviews were selected to provide enough content for comparative analysis but enough flexibility to capture and respond to areas of interest that were uniquely or independently raised by the interviewee. They yielded keywords and concepts I could explore in subsequent activities.

## 3.4 Workshops

### 3.4.1 Speculative design workshop

Boobs from the Future was a mixed-gender speculative design workshop with non-prosthesis wearers in which I asked:

- What if a prosthesis could enable someone to do something they couldn't before surgery?
- What if a prosthesis could equip people for surviving or thriving in the future?
- What if a prosthesis provided such benefits that it might inspire someone to undertake surgery voluntarily?

The intention was to generate ideas from an outsider perspective (non-prosthesis wearers) for how the EBP could be different in future. During this workshop I sought to:

- explore how prosthetic breasts could become functional, as opposed to merely cosmetic
- gather contemporary cultural meanings of the breast from a variety of perspectives
- generate a range of ideas on how breasts and prostheses could be different in the future
- stimulate imagination
- dispense with assumptions



The main workshop took the format of a condensed design sprint, comprising solo idea generation, group affinity-mapping and dot-voting, followed by team-based idea development, prototyping and pitching.

Current prosthesis options were framed in an archive setting. A theatrical setting with lighting and props was used at the start of the workshop to stimulate the imagination and remove connection with regular sense of time and space.

Each participant was handed a research kit as they arrived containing “Future Vision” glasses, research/stimulus questions, prompt cards, folded paper, sticky stars and coloured pens.

Design thinking uses the idea of “extreme users” as being able to provide valuable insights. While atypical of the standard user, by merit of being outliers, they can provide new ways of understanding both the common experience and how it could be different. In some cases, by listening to outliers, features or benefits may be uncovered which would appeal to all or most users in time.

## **Learnings**

Five themes emerged among the ideas generated which were grouped as technical, medical, sensual, sexual and parenting. Participants were most interested in ideas for a prosthesis that could either provide parental gender-equality during breast feeding or enhanced sensuality, restoring and enhancing sensing capabilities of the

wearer. While the ideas generated did have a basis in current cultural ideas of the breast: parenthood and sensuality/sexuality, they did represent a progression beyond socially and physically defined current limitations of what the breast or prosthesis can be which was exactly what I had hoped for.

### 3.4.2 Co-design workshops

Bosom Pals Creative Workshop was a women-only personalised design workshop for five prosthesis wearers from Bosom Pals breast cancer support group which I ran at University of Plymouth.

Creative Workshop for CanCope was a women-only design workshop for four members of CanCope breast cancer support group which I ran at the group's regular meeting room in Exmouth, Devon.

The intentions of these workshops were to explore how meaning can be created through making a personalised prosthesis, to understand women's priorities for their prosthesis and their self-image, and whether being involved in creative activity around the design of the prosthesis might shift wearers feelings about their prosthesis.

The workshops posed these questions:

- What words would describe your ideal prosthesis and your experience of wearing it?
- What if your prosthesis could capture a personal message from a loved one, a special image or something else meaningful to you?
- What if your prosthesis were coloured or decorated in your favourite colours or patterns? What if it could express your identity and personal style – what would it look like?
- How might we change the structure of the prosthesis to make it more comfortable or adaptable?

- How might lingerie design translate into a new design for a decorative prosthesis?

The workshop comprised reflective activities about the prosthesis and each woman's emotional journey during cancer treatment, before moving onto a designing and making activity.

Participants brought pre-prepared personal visual stimulus to the workshop to inform the 2D designs and 3D prototypes they created of a personalised prosthesis.

Prior to the workshop, participants were sent a preparation activity via their support group leader. They were asked to gather objects or images that reflect things they like the look of, and or that hold personal meaning.

Having visited Bosom Pals three months' prior and found them positive to the idea of a colourful, decorative or personalised prosthesis, their workshop delved straight into what a personalised prosthesis might be like and what it might mean.

With CanCope, we followed up on themes that had emerged during my first visit 2.5 months earlier. Group members had impressed upon me that the weight (heaviness) of the current product needed addressing and that there was a strong desire for pretty and feminine post-surgery lingerie (they had also responded positively to the lace-like model I had shown).

Consequently, I focussed materials and activities on helping them explore and create

personalised lace designs or communicate what could be improved with existing prosthetics - e.g. ventilation, reducing the weight in places, etc.

At both events, I started the workshop by capturing participants' conscious feelings about the EBP. I asked participants to describe their prosthesis, then themselves and to note down how others described them and their prosthesis. Separating participants' voices from those of others allowed me access to ideas or attitudes that participants may have absorbed into their own thinking or were influential on their outlook. Identifying and separating them brought these different viewpoints and sources into consciousness.

By separating perspectives of self from perspectives of others, I could gain further insight into the participant, inspired by an NLP<sup>21</sup> coaching technique: perceptual positions, and by Jungian theory, where some elements of self may be projected onto others because it may not be comfortable to acknowledge or own these descriptions as belonging to self.

## **Learnings**

When I provided women with the choice to explore their own personal meanings and identities through a prosthesis design, everyone created something quite different, suggesting that women are wearing the same type of prosthesis, not because they want to, but because this is all that is currently on offer.

The notion of a universal feminine aesthetic - something that seemed to be arising

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<sup>21</sup> Neuro Linguistic Programming

from the CanCope discussion - was challenged by one participant when she said, “not everyone likes the colour pink”. She felt it was important to do away with assumptions around gender stereotypes. The continuation of a predominant aesthetic for prosthesis could just as easily be due to heavy assumptions that are continually reinforced and gradually become the accepted norm. The workshop’s purpose was therefore validated because of course women (like anyone else) like different things and there needs to be the opportunity to capture converging and diverging design preferences to, where possible, provide more variety.

### 3.4.3 Co-design student workshop

This student workshop was a mixed-gender design workshop for nine BA and MA students from the School of Art, Design & Architecture (non-prosthesis wearers), with stakeholder mentorship from a member of Bosom Pals.

The intention was to provide design students with experiential learning of co-design principles and to encourage students to continue with this approach as they enter industry or form their own professional practice.

The workshop posed these questions:

- How might we create better user-experiences for wearers of prosthetic breasts?
- How would prosthesis packaging be different if we considered not just the cost but the person using this object daily?

Students were provided with two wearer personas and asked to select one to design for. Encouraging students to work together and focus on the user rather than their own design interests or creative expression was important for generating an understanding of empathic and collaborative design. Having the user present and asking people to work in small groups were ways to demonstrate these values.

The workshop followed a similar format to the speculative design workshop in terms of object handling, idea generation, voting, prototyping and pitching. Participants looked at and touched existing EBP and packaging and heard from the researcher

and Bosom Pals member about what women think of their prosthesis and how breast cancer has affected them, before moving into the condensed design sprint format.

Forging relationships between consumers and designers is essential if we are to foster understanding and encourage emerging product designers to take a human-centred design (HCD) approach. By providing experiential learning of co-design principles, the workshop was an introduction to potentially shifting the mindset of the students by making consumers and their pain points real rather than abstract.

As my approach was discursive, it was important to engage stakeholders with the research. Emerging designers were invited to a workshop to re-imagine a product that they might not have otherwise known about and interact directly with a wearer to understand her experience.

Inviting Bosom Pals to mentor or adjudicate was designed to deepen members' relationship with the project and evidence that I have absorbed their comments and am motivated to seek solutions.

## **Learnings**

Young and emerging designers recognise the value of customisation and the impact of aesthetics on user experience. A co-design workshop can be educational for both designers, researchers and stakeholders, as each brings their unique skills, experience and viewpoints to the conversation. Introducing this form of working while



still in the supportive environment of formal education can support students to absorb new habits.

A few weeks after the workshop I met with 3 of the students, rather than doing an electronic survey as I have done previously. Some of the students' comments strongly emphasised what a difference it made to have someone who would wear the product in the room with them and they even said it would have been great to have had more time with her so that she could speak to them and answer questions. For some of the students, it really made them think about the importance of considering who would use the product they were designing, and they thought it was great to have someone right there to talk to, to confirm ideas and provide direct feedback and stimulate new directions of thought.

Students were positive about the benefits of working together, including the range of perspectives gained by having people from different disciplines, ages and cultures together. They found the groupwork approach an unpressured experience, and collaborative rather than competitive. I was pleased to hear that the collaborative elements were appreciated as I believe by designing together, we can create products that are not only satisfying for the designers to (co-)create but also fit for purpose and truly human centred rather than egotistical. One student found my approach of generating ideas alone before combining and synthesising them to be so inspiring he went on to apply that same approach in his own research workshops.

Based on this feedback, it seems that my intention to model co-design was well

received and the benefits of it as a working method were understood and appreciated.

It was great to hear people talking about the need to consider the user more in what people make or that emotional design was an important thing to someone now.

The Bosom Pals' mentor was encouraged by the students' creativity and careful listening:

*"In terms of empathy it was particularly pleasing to see that one of the students wore the mastectomy bra with prostheses for some time and appreciated the impact the weight of the prostheses had on her back. Another had actually adhered one of the prostheses to her own skin, to feel the effect of this type of appliance."*

*"Clearly the group could see little point in the prosthesis being flesh-coloured, as it would not be visible when worn. Indeed, the advantage of the item being more decorative could serve the purpose of it being less recognisable as a false breast, and more similar to an item of pretty underwear when not being worn."*

### 3.5 Remote

The remote activity pack adapted and built on creative workshop activities and combining some of the same elements as used with probes (section 3.6).

Participants were four women from around the UK who wore a prosthesis, including at least one woman of colour<sup>22</sup>. The women were recruited via Facebook.

Participation in workshops was limited by geography, so I decided to create an alternative mode of participation by providing a remote activity pack that would provide the opportunity to capture potentially alternative perspectives from women in other parts of the UK, and other parts of the world. Additionally, as the activity pack could be completed at a self-determined pace, I expected that the more reflective process would provide me with deeper insights.

Part of the intention of the remote activity was to compare methods of exploring visual preferences and personal meaning remotely with those achievable within a workshop context.

Remote activities were sent after the workshops allowing me to refine worksheets and activities, focus questions more, and create additional activities to ask questions that had arisen from previous workshops or interviews, such as exploring requirements for a swim prosthesis and what it might take for a wearer to feel comfortable about her prosthesis being seen in public. Most activities offered in a

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<sup>22</sup> Racial data were not collected, but one participant spoke to me about her experience of prosthesis as a woman of colour and the concerns of other women of colour she knew.

workshop could be adapted for the activity pack.

The activity pack comprised a set of postcards with one question written on the back of each (essentially a questionnaire), a photograph with prosthesis models on and an accompanying survey, and some reflective worksheets and creative worksheets. Participants had a month to complete the pack.

There is a limit to how much can be covered during a workshop, both in terms of logistics and mental and emotional energy. Combining a larger range of activities over a longer period with guidance on grouping tasks, I anticipated getting more useful responses and better engagement levels with each activity as people would be approaching it fresh and tackling the same type of activity as batched work, rather than asking people to switch “mental modes” and work in multiple ways within a short period of time.

Not all participants were interested in the idea of a decorative prosthesis and this not only provided useful insights into women’s varying requirements of an EBP, but also yielded concepts for alternative and adjunctive products. This demonstrated the value of encouraging a diversity of perspectives. Additionally, by broadening the geographical scope it allowed for some ethnic diversity among participants which contributed new insights into what the prosthesis could mean.

### 3.6 Probes

The Design Kit was a remotely delivered project I designed and delivered with six prosthesis wearers in Hayle, Cornwall, who attend St Michael's Breast Cancer Support Group, informally known as the Foxy Ladies.

The intention was to explore how people respond differently when they complete activities at their own pace, and the degree to which it is personally revealing.

The results would enable me to compare remote and flexible activities (design/cultural probes) with time-bound shared-space activities (workshops) and compare the quality and usefulness of generated data and ideas.

By capturing reflections over a period of time, design kits were able to better capture a wider range of women's emotions and experiences than in the time bound context of a workshop.

Each participant was provided with a design kit – a handprinted paper bag containing a camera, journal, adjective cards, rubber band, sticky stars, pens, postcards, treats, activity sheets, welcome letter and a stamped, self-addressed envelope to return the completed kit to me.

The purpose of the design kit was to understand something of women's experience of wearing and owning a prosthesis, understand what this means to women and maybe to those around them, and to capture a sense of participants' personal style

and visual identity to inform the prototype prosthesis exhibition objects I was intending to make.

By having more data and user-selected data to go through, the designer-researcher can get a richer picture of the person and understand how to create either a design that matches participant themes or that acts as an antidote.

For the designer and maker, the design kits or design probes proved their worth as a source of inspiration, visual stimulus and provider of themes and narratives, when it came to the data analysis stage.

### 3.7 Analysis

In practice-based research, original data comes from multiple sources: in my case there was reflexive data which arose from my making and journal-writing; tacit knowledge that arose through observing and handling EBP; emotional data from participants and my own empathetic response to it; textual data from interviews, informal conversation, correspondence, questionnaires and participant journals, and visual data from participant generated designs, prototypes, photographs and collages. In this segment of the thesis, I introduce my approach to a selection of data analysis and what I learned from it.

### 3.7.1 Analysis of cultural artefacts, practices and media representation to inform discursive designs

Before gathering any data from participants, I first looked to “cultural data” to examine what might be possible for the EBP.

A cultural context for the practice began with reading sociological and feminist literature on tattooing and body modification. The intention was to understand some of the meanings individuals and communities ascribe to these practices, and how the persistence of these practices gradually extends beyond the original cultural group to pervade other cultures or in the case of sub-cultures, mainstream culture.

To understanding the cultural context of prostheses in general, I visited various prosthetics websites and performed a comparative discourse analysis of limb prosthesis websites to EBP websites (see appendix G). Which exposed a marked difference in discourses. My reading of the current EBP discourse supports the findings of Cromptvoets, 2012.

I considered more generally the media representation of the breast, in fine art, and in print and digital media. I identified that the breast is variously considered in functional, aesthetic and ideological terms, depending on the context it appears in and who is doing the considering.

A rich source of understanding about the meaning of objects was gained from an object analysis of dildos, along with quantitative and thematic analysis of consumer preferences around the aesthetics of dildos. I supplemented this with a review of



existing quantitative and qualitative data on sex toy retailer's website (see appendix J). Finally, I made a brief study of literature (Wilner & Huff, 2017), (Glover 2013), and web-based feminist commentary on the cultural, commercial and design evolution of sex toys.

In studying dildos, the intention was to examine an object that - like the EBP is to a breast - resembles a disembodied body part. The objects have in common that they are typically not used or displayed in public and are considered at least somewhat taboo. By looking at the diversity of aesthetics available and whether this has changed over time, I intended to understand if there might be any transferable insights for helping to change the personal and social meanings of the EBP.

I took a mixed-methods approach to the consumer data, examining a discussion of coloured versus realistic dildos in a sex toy retailer chatroom, quantitative survey results on aesthetic preferences relating to coloured versus realistic dildos, and then compiling my own quantitative consumer dataset from a sex toy retailer's website, comparing popularity scores for various dildos according to both frequency of purchase and ranking.

I conducted a comparative visual analysis of dildos available in a high street retailer versus a back-street "sex shop" - including the retail environment, packaging and the product itself. I compared these phenomena with a recalled experience of 20 years earlier, feeling bemused when I visited a sex shop to buy a bodice for a fancy-dress party and noticing a line of oversized, veined pinkish-beige dildos on a shelf.

In the 20 intervening years between my visits to sex shops, the diversity of

aesthetics in dildos had indeed changed. “Realistic” options were still available, but these were now joined by realistic form with unrealistic colour and fully stylised dildos that were not anatomical in either colour or form.

I concluded from the quantitative data analysis and my observations of changing aesthetics that consumers now have much greater choice and that some people prefer realistic forms and colours while others do not, to a varying degree. The qualitative analysis of the forum content provided deeper insight into the feelings some people have about coloured and skin-toned toys. The net effect was a basic level of understanding consumer attitudes towards anatomically associated objects,

These various sources of cultural data provided a backdrop from which I could extrapolate knowledge to inform the development and fabrication of speculative and discursive objects and frame discussions about the future directions of EBP, by considering how cultural meanings, media representation and social acceptance of taboo objects change over time (Wilner & Huff, 2017).

### 3.7.2 Analysis of participant narrative themes, visual preferences and emotional journeys, to inform the design of critical exhibition objects

In my initial analysis of participant data, the purpose of which was to inform the design of exhibition objects, I did not use an empirical method of interpreting research data to determine participants' individual aesthetics<sup>23</sup>. I could have used Sansoni's repertory grid (Sansoni *et al.*, 2016)<sup>24</sup> to determine what participants wanted, but as she used hers for limb prostheses which are on show and are functional, and I was working on breast prostheses which are less functional and generally hidden, I did not want to assume that her terms would apply. By gathering words and visuals from the participants I could have eventually formed my own repertory grid for prosthetic breasts, but at this stage I was looking to develop something rather than apply an existing model. I did not want to impose something existing but rather find out in the words (and images) of participants, what they wanted.

Using my colour psychology training, I ascertained each client's colour palette according to the Wright Theory (Wright, 2009), which according to the theory provides additional insights into preferences for textures, form and material which would be relevant when developing a bespoke wearable prosthesis, but which was

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<sup>23</sup> I did go on to do this later, a discussion of which can be found in section 3 of appendix I, starting pp. 218.

<sup>24</sup> A repertory grid contains pairs of opposing terms, arranged in a grid formation with space between the terms. The respondent will place a mark somewhere between the two terms to spatially indicate their degree of preference for one term or the other. An example might be a survey on preferred temperatures of liquids in different contexts. To survey preferences on the preferred temperature of bath water; the pair of terms would be cold and hot and a respondent who likes a luke-warm bath would place a mark in the centre between the two points whereas a respondent who likes very hot baths would place a mark directly under the term hot.

not a priority within the creation of exhibition objects whose main role was to generate conversation.

I looked through any designs they had produced (2D or 3D), any written descriptions in notebooks or worksheets and the adjective cards they had selected, treating it all at this stage as creative stimuli. In some instances, I would take inspiration from physical objects, lifting a pattern which I repeated. In others, I took a lateral approach, meditating on the different stimuli I had gathered until I came up with a theme. In other instances, I created exactly what the participant described she wanted. By taking a range of approaches I would later be able to assess each for efficacy and select an approach I could then develop empirically so that others could use and repeat it.

By immersing myself in multiple forms of participant data I was able to extract nine themes of possibility for future EBP, which, added to my own realisation from making that a prosthesis need not be solid, resulted in ten statements of what the EBP could become which were then displayed at the exhibition, *Becoming*, (see appendix D for a description of all ten).

The process of reflection in preparation for making was revelatory in that I had not previously been aware that themes and new insights could arise from the data, nor that these less traditional forms of data could be so fruitful. These same data proved to be even more rich when I eventually returned to them to perform a more thorough and systematic analysis, which yielded among multiple other insights, new product ideas and wearer profiles, from qualitative analysis of quantitative data, and four

themes for improving the wearer's experience (see appendix H), which arose from thematic analysis, a technique I cover briefly in 3.7.3.

## **Learnings**

It is worth designers and manufacturers considering how life stages, lifestyles, relationships and time since mastectomy all influence what a woman wants from a prosthesis and consequently, differentiation in product offer and messaging is sensible. Asking several women their preferences for an EBP and receiving divergent answers that suggest entirely different product styles and aesthetics, supports the argument not only that women should be provided with more choice but that engaging the wearer in the design process can unlock product innovation. (see appendix I, section 2 for co-design section of data & analysis).

### 3.7.3 Thematic analysis overview

Understanding the emotional journey of a product or service user can inform the development of an empathic design and in turn hopefully create a more positive experience for the user.

I conducted a thematic analysis of participant descriptors of themselves at different stages of their cancer journey (see table 1 for a sample of the data and appendix I for further detail). I reflected upon this analysis in preparation for making exhibition objects for Becoming (see section 3.8 and appendix D) to consider how it might be possible to move the wearer from column 3 towards column 4.

**Table 1: Sample participant self-descriptors at different stages of their cancer journey**

|    | <b>1. Before</b> | <b>2. During</b> | <b>3. Now</b> | <b>4. Ideal Future</b> |
|----|------------------|------------------|---------------|------------------------|
| 4A | Ordinary         | Freak            | Bereft        | Normal                 |
| 2A | Sexy             | Struggled        | Mutilated     | Free                   |
| 2D | Confident        | Dying            | Battered      | Body Confident         |
| 5D | Optimistic       | Dark             | Fragile       | Happy                  |

Subsequently analysing the descriptors, I grouped them according to five apparent themes which reflect the negative aspects of their experience (see table 2).

**Table 2: Analysis of words shown in the Becoming exhibition**

| <b>VITALITY - I</b><br>have lost my<br>former vitality | <b>ATTRACTIVENESS</b><br>- I am unattractive | <b>WHOLENESS - I</b><br>have lost an<br>essential part of<br>myself; I am no<br>longer whole and<br>(maybe) never will<br>be | <b>MEDICAL<br/>VIOLENCE - I</b><br>have been<br>brutalised to make<br>me "better" | <b>STRENGTH &amp;<br/>CAPABILITY – I</b><br>am weak, in body<br>and in mind |
|--|--|--|---|---|
| Aged   | Ugly   | Broken   | Medicalised   | Unfixable   |
| Weak   | Freak  | Beaten   | Chemical Pit  | Useless   |
| Fragile  |  | Unfixable  | Mutilated   | Beaten  |
| Disintegrating   |  | Bereft   | Battered  | Broken  |
| Dying  |  | Incomplete   | Maimed  | Pathetic  |
|  |  | Fragile  | (Beaten)  | (Weak)  |
|  |  | Partial  |   | Fragile   |
|  |  | Disintegrating   |   | Wrong   |
|  |  |  |   | Incapable   |

By drawing out the themes of vitality, attractiveness, wholeness, medical violence, and strength and capability, it provides a basis and invitation to designers and healthcare professionals to consider how to create products and processes whereby a woman can feel more vital, more attractive, more whole, more cared for, more capable, and physically and mentally strong after mastectomy.

### 3.8 Exhibition (Becoming)

Becoming was a public exhibition which I curated and installed in the second-floor gallery outside the design studios in Roland Levinsky Building, University of Plymouth. The exhibition comprised a text installation, a lighting and data visualisation installation, 10 re-imagined EBP models, a section showcasing co-design approaches and workshop and remote activity artifacts, and a space to handle prostheses and implants to understand their texture and weight.

Becoming proposed a series of antidotal designs (see 2.6, 4.3.2), exploring the concepts of beauty, function and the physical and psychological transformation that women undergo with mastectomy. Instead of rooting the trauma of surgery and loss in a semi-realistic object (an EBP), I took as my brief the word "becoming", encapsulating as it does, three definitions: visual appeal, appropriateness and the act of transition.

The intention of the exhibition was to raise awareness of women's experiences of breast cancer and prosthesis, celebrate participants' ideas and contributions, stage a provocation to designers to design better and for prosthesis wearers to demand more, and to publicly disseminate the core messages of the project. The exhibition was intended to be inclusive and interesting to a wide range of people, ages and backgrounds.

To engage participants with a microcosm of the thesis and my methodology, the



material was divided into five sections: cultural background, empathy, re-imagining, co-design, with small interactive design area to one side. Attendees entering the gallery space through the main or right entry points would join the exhibition at its intended start, and could follow the route of the exhibition, mirrored by the route of my research. First reading a reflection on the status quo, they could then gain insights into women's self-image after mastectomy, handle prostheses and so understand a little of women's experiences, arrive at ten alternative prosthesis concepts and ending with co-design and the opportunity to generate their own designs. Conversely, if attendees entered through the left entry point, they would be able to experience the research trajectory in reverse, travelling from colourful, joyful and imaginative designs, past the silicone gel prostheses and implants, past the wall describing women's negative experiences in their own words and arrive finally at the cultural background section, bringing them to the present date. Either direction of travel would cover both prosthetic realities and prosthetic futures and provide the opportunity to reflect on how things are and how they could be different.

Choosing to describe my contribution to the show as that of curator, having interactive activities and involving design students from two local arts institutions in the production of some of the displayed work, I sought to exemplify the principles of creative collaboration.

## **Learnings**

The exhibition represents a missed learning opportunity to gather further insights. Had I had sought out participant responses to the concepts communicated at the exhibition, I could have learned from the participants the effect of seeing their

experiences and desires reflected back to them, not orally, but visually, and for this to take place in a public setting. Additionally, by not capitalising on the discursive potential of the exhibition, I missed the opportunity to understand how well I had captured and conveyed women's stories and to capture any new ideas or insights that arose in response to seeing the work and learning about other women's experiences. However, this possibility will be renewed with the circulation of this thesis to participants.

### 3.9 Chapter conclusion

In this chapter I provided a descriptive, analytical and critical account of my practice-based research, justifying the methodology and decisions made, and identifying what I learned, its applications and limitations. The approach, although using multiple methods and iterative in nature, was broken into seven segments so that each could be examined in turn. In the next chapter, these discrete accounts of learning are brought together in synthesis.

## **CHAPTER 4: SYNTHESIS: Prosthetic Realities, Prosthetic Futures**

### 4.1 Chapter Introduction

In this chapter I synthesise learnings from my practice-based research. The text is split into two segments: the first is prosthetic realities, which summarises the current processes, priorities and mindsets of women who wear an EBP; and second, prosthetic futures, which suggests future directions for EBP design processes and consequent meaning.

## 4.2 PROSTHETIC REALITIES: women's experiences of deciding whether to use an EBP

### 4.2.1 Processes and priorities

Woman's experiences and choices after mastectomy vary hugely. Captured below is a diverse range of thought and social processes through which women go after mastectomy to navigate whether to wear an EBP or not. Decisions made by each woman reflect her primary concern, and as such, the diversity of concerns below demonstrates that assuming all women share the same primary concern for realism is misguided:

1. Some women do not feel an EBP is necessary after mastectomy and so do not wear one. This choice reflects a degree of security in gender identity and social relationships. (primary concern: **resistance of stereotypes and cultural norms**)

2. Some women feel incomplete without a breast or that it would be socially detrimental not to have one and so have reconstructive surgery (primary concern: **self-concept -- complete**)

3. Some women cannot or will not have reconstructive surgery but choose to wear a prosthesis in order to preserve a semblance of completeness. (primary concern: **social conformity**)

Of this third group, the experience of wearing a prosthesis is not unanimously positive:

3.1 Ultimately, some women reject the artificiality of the EBP so they

3.1.1 don't wear it or (primary concern: **authenticity**)

3.1.2 explore private bespoke hyper-realistic prosthesis (primary concern: **realism**)

3.2 Many women reject the weight of the EBP or find it is uncomfortable so wear something lightweight (against medical advice) (primary concern: **comfort**)

3.3 Some women wear a prosthesis only when in public to “keep up appearances”, but at home or in social circumstances where their mastectomy is known about and is accepted, they will not (primary concern: **social conformity**)

3.4 Some women find buying replacement prostheses expensive; so they will wear a swim prosthesis, knitted knocker or softie instead (primary concern: **expense**)

3.5 Many women resent re-entering the medical system each time they need a new prosthesis (usually every 2-3 years because the surface splits). Rather than do so, they will:

3.5.1 buy something online (without being fitted by a specialist)

3.5.2 wear an old prosthesis

3.5.3 improvise with something else – household objects, handmade breast form, knitted knocker. (primary concern: **medical independence**)

3.6 Many women experience their remaining breast changing as radiation therapy continues to shrink the remaining breast, as they lose or gain weight, or as the skin loses its elasticity with ageing. These all result in a lopsided appearance which can be distressing but is not provided for under the NHS eligibility criteria for a new prosthesis. This causes women to do one of the following:

3.6.1 buy something online (without being fitted by a specialist)

3.6.2 wear an old prosthesis

3.6.3 improvise with something else – household objects, handmade breast form, knitted knocker

3.6.4 keep wearing the prosthesis that doesn't fit, keep looking lopsided.

3.6.5 go private (primary concern: **control over appearance**)

These women may want to re-enter the medical system in order to access a new EBP, but they are not eligible, so the above choices are made from necessity, not desire.

The concerns raised in section 3 above provide a range of factors for designers to consider if they wish to explore how to create a better wearer experience for those women who choose to wear a prosthesis but currently find it unsatisfactory.



## 4.2.2 Mindsets after mastectomy

Here follow five differing mindsets which women might have after mastectomy.

Product requirements vary according to mindset, so designers need to be aware of the following to understand how to meet women's needs and to be aware of what opportunities exist.

### **MINDSETS AFTER MASTECTOMY**

#### **Five themes, five theme tunes...**

##### **1. Hide Away**

The first mindset, with the theme of **disguise**, arises in data from cultural probe journals (see 3.6), a specialist Facebook support group and informal conversation.

Some of the women I have spoken to speak of hiding their chest or disguising themselves. Be this through draping of scarves to obscure the chest, layering their clothing or adopting a different style of dress, some women feel it is not acceptable to show a change to their body in public. For others, they would like to dress as they did before but find that because of the style of the prosthesis and how it behaves in a bra, they are limited in what they can wear, and low-cut styles are now off-limits.

##### **Commentary/Application**

If society were more accepting of bodily difference, if the prosthesis looked different – perhaps like an item of clothing – or if the prosthesis were something delightful, then perhaps there would be less of a drive to hide the prosthesis away or to dress

differently, and the new prosthesis could either be proudly displayed or at least not a source of embarrassment if it did show.

## **2. Que Sera Sera**

The second mindset, with the theme of **stoicism**, arises in data from discussions with Can Cope and individual interviews.

Some of the women I met during my research were quite stoical about their prosthesis. There was a degree of “just getting on with it” and a “like it or lump it” attitude. Especially for those women who accessed a free prosthesis via the NHS, and for those who have grown up during or in the wake of a “make do and mend” wartime mindset, the notion of disrupting something that works adequately and has been given free seems alien, or at least not worth the emotional effort - since attention is best placed on resuming regular life.

### **Commentary/Application**

According to consumer profiles, divided by sociologists along generational lines, women of a younger generation (as well as - it should be noted - some of an older generation) do not share this same attitude and are demanding consumers. They are not the type to settle and would not accept a ‘it’s not broke so why fix it?’ mentality.

## **3. Express Yourself**

The third mindset, with the theme of **self-expression**, arises in data from discussions with Bosom Pals and Foxy Ladies, the workshop with Bosom Pals and the remote packs (see 3.5).

For women who may dye their hair, wear makeup, wear stylish or unusual clothing, identify as alternative, fashionable, creative or unconventional, there is an interest in self-expression, in communicating messages to the outer world about the inner self. For women with this mindset, the prosthesis is an opportunity to do something different and adopt an attitude of 'why should it be boring and ordinary when it could be fabulous?'.

#### Commentary/Application

This mindset is currently not addressed by conventional EBPs and this research intends to highlight that this is a market which can be addressed, for the benefit of women.

#### 4. Look At Me

The fourth mindset, with the theme of **pride/exhibitionism**, arises in data from interview with Paul Singleton, Facebook adverts and cultural/business data – looking at how sub-cultures gradually become mainstream.

Outside of the participants in this project, it is entirely possible that there are some women whose primary concern with their prosthesis is aesthetic. Women with this mindset would be open to avant-garde designs, comfort would be no matter if the look were right, leaving the designer fully open to run wild with their imagination. While this would be a fashion designer's dream, it does not reflect the concerns of the women I spoke to. Thus, an example of this has not been represented within my practice, as much as I would have loved to create something fantastical.

## Commentary/Application

The psychological affordances of publicly wearing such a product could be transformational, but the audience who would embrace this product concept may not yet have developed breast cancer. That said, some communities who already embrace a more exhibitionist attitude, or who would view the prosthesis as an enhancement opportunity, already exist, so perhaps this is where this movement would begin. Indeed, we are one step closer to this as the concept has already been embraced with a new product called Breastflower<sup>25</sup>, which is a luxurious fabric accessory that can be worn against the skin over the mastectomy scar and is designed to be seen, as well as enjoyed privately by the wearer.

## 5. Don't Make Me Over/Accept Me For What I Am

The fifth mindset, with the theme of **resistance**, arises in data from images on Facebook groups and responses to the dissemination of my practice. I spoke with artists in Plymouth, London and New York who occupy this mindset; connections forged as a result of sharing images, written description or public speaking about this research.

The mindset hardest to reach from a commercial perspective is that of the woman who questions her need to wear a prosthesis at all. From her position, the absence of her breast or breasts is not an issue. Breasts do not define her femininity and she is no less of a woman if one or both breasts are gone; the onus is on society to change its attitude, not for her to step in line and conform with societal

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<sup>25</sup> <https://www.breastflower.com/en/about-breastflower/> A fantastic new product with a refreshing take.

expectations. I have considerable sympathy for this mindset.

#### Commentary/Application

The creative response to this mindset is to design apparel differently. There is appetite for bras, swimwear and clothing that fit the post-mastectomy body. Without a doubt, this does pose some engineering issues; and of course, every woman's body is different, and mastectomy surgeries have widely varying outcomes. I suspect that as the fashion industry continues to move towards more sustainable production methods and increases its use of smart technology to create custom apparel, we will see new designs emerge. Conceptual projects such as the monokini 2.0<sup>26</sup> provide a good place to start for inspiration.

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<sup>26</sup> <http://www.monokini2.com/>

## 4.3 PROSTHETIC FUTURES: aesthetics and design process/practice

#### 4.3.1 A grounded theory of the aesthetics of EBP

- Realistic aesthetics are highly desirable to some wearers for personal psychological reasons (feeling like your former self, not about others' opinions) and for social reasons (looking like your former self to fit in socially)
- Non-realistic aesthetics are highly desirable to some wearers who respond negatively to what they perceive as an unsuccessful attempt at realism of the standard EBP and who may also place importance on expressing themselves through their choice of colour/pattern/design.
- Aesthetics are not at all important to some wearers; it would equally not matter if the EBP is skin-toned, had a surface/integral pattern or was non-skin-tone-coloured.
- Aesthetics in a superficial sense are not important to some wearers but the offer of including an element of personal meaning, such as a message from a loved one, transforms the concept of a non-realistic prosthesis into an appealing prospect.
- Self-expression through colour and pattern is not a priority for some women but the concept of a lingerie-like EBP does appeal. For both aesthetic and practical reasons (such as avoiding embarrassment due to unplanned public exposure), adopting a realistic aesthetic can be the right approach if it seeks to emulate lingerie rather than the bare breast.
- Whether aesthetics will matter to some wearers depends on context. When there is the potential that the prosthesis is seen by others, it does matter to some wearers – the prosthesis should either pass as a breast so as not to be easily noticed or look so unlike a breast when detached from the body that it does not attract questions e.g. at a leisure centre. However, in private, when

only the wearer is seeing her prosthesis, the aesthetics of the prosthesis may not matter to her.

- Some wearers do not place importance on aesthetics for their own consumption. Others, however, understand the symbolic value that a beautiful, expressive or personalised prosthesis could provide, and acknowledge they could derive pleasure, reassurance or inspiration from it.

The research demonstrates that designers could provide more diversity in both aesthetics and personal meaning for the EBP. By expanding their design practices to include the wearer, designers could create new prosthetic futures for wearers of EBP. (See section 4.3.3 and 4.3.4).



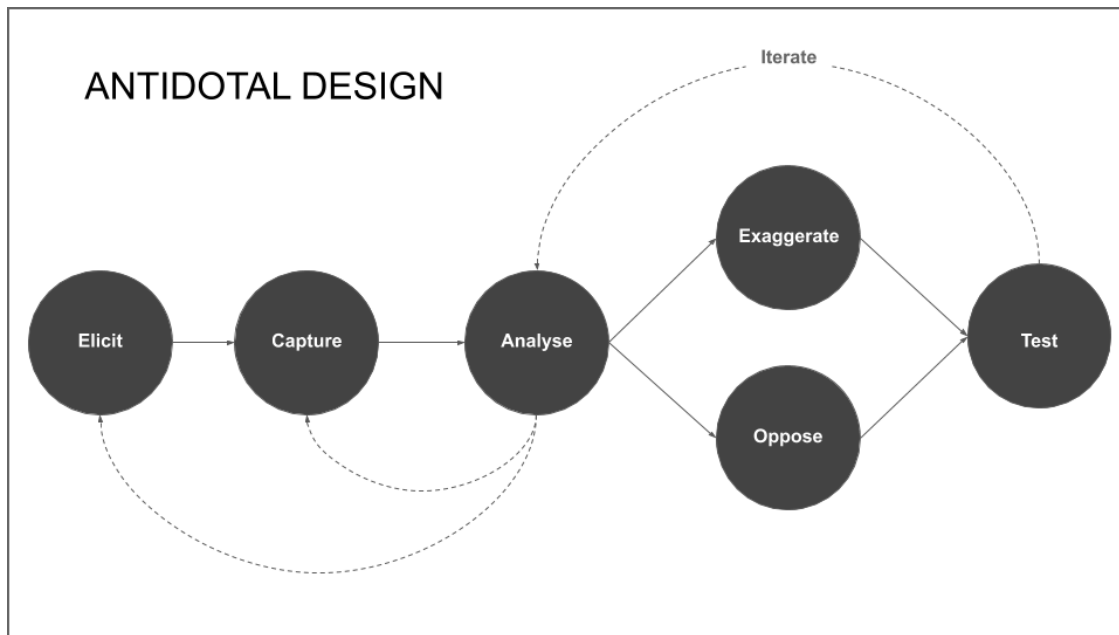
### 4.3.2 A model for antidotal design

This model for antidotal design is inspired by analysing participant data and reflecting on possible emotionally-driven design responses. The intention is to use design to acknowledge and then shift user attitudes away from those they find negative, destructive, or unhelpful. Through continued interaction with the newly designed artefact, the user can break the cycle of negative reinforcement that comes from repeatedly activating the former emotional trauma, association, or pattern of behaviour, and instead re-route her focus towards something she finds desirable, positive or helpful, activating positive associations each time it is used (Csikszentmihalyi & Halton, 1981).

Because this process involves elicitation of emotional data, there are ethical implications. There are issues of data management, emotional welfare of the client and practitioner safety and competency. Due caution calls for partnership with trained specialists in psychology or psychotherapy who subscribe to a professional code of conduct and ethics and are held accountable to professional bodies.

The prospect of partnership should not dissuade exploration of this model; as this research has demonstrated, collaboration provides synergistic benefits.

Multidisciplinary teams of psychologists, designers and user researchers will become increasingly common in the design of products, services, environments, and processes as companies change their business models to become more user-focussed to remain competitive (Margolin, 2016).



**Figure 2: A model for the proposed practice of antidotal design**

A basic guide to the responsible use of the antidotal design model (Figure 2):

- 1) **Elicit** emotional data, ethically and sensitively, from your client. Consider partnering with a specialist.
- 2) **Capture** the client's visual preferences, and personally meaningful text or images, to provide you with design stimulus.
- 3) **Analyse** the emotional, visual and textual data. Identify themes and key concerns.
- 4) **Create** a design which addresses emotional and personal themes and add any elements you believe will counter the original emotion. Either a) exaggerate these so that you extend or strengthen the original concept or b) oppose them.
- 5) **Test** your ideas with the client; then **iterate** your process accordingly.

My own application of this model within the confines of this research is limited to the first four stages only. Further work is required to move this into the test phase and iteration which, I regret, was not explored as part of this research project but which will certainly be integral to my research design and practice in future.

### 4.3.3 Summarised Design Guidelines for External Breast Prostheses

The following considerations are synthesised from participants across the research project and address material, aesthetic, psychological and user-experience concerns:

**Differentiation** – lifestyle, recency of surgery, income, cultural background and mindset all create differing requirements - as with all other products, provide the wearer with choices.

**Choice** - choice is particularly important at this time when so many choices have been made for the woman. The provision of choice here is more than just luxury: it is psychological empowerment.

**Adaptability** - women have varied lifestyles that mean that what they need from a prosthesis will change from day to day or within a given day. Instead of requiring a woman to put up with one style of prosthesis that doesn't suit all her needs and therefore limits her lifestyle or requiring her to purchase multiple prostheses for each requirement, give attention to how a single prosthesis might be made adaptable, allowing the wearer to adjust fullness, weight and so on according to her needs and preferences.

**Comfort** – make the addressing of issues surrounding temperature, moisture control and weight, a standard for all prostheses, not just specialist products.

**Security** - explore surface textures that assist the prosthesis with staying in place within the bra rather than just trying to mimic skin.

**Durability** – the current lifecycle of the EBP is short. Consider alternative materials and or structures that would enable the prosthesis to last longer and perform better.

**Accessibility** – consider the ways in which the EBP could be made available without repeated engagements with medical professionals.

**Affordability** – consider the ways in which the EBP manufacturing process be rethought to produce a more affordable product.

**Holism** - consider how the prosthesis could help a woman feel more vital, more attractive, more whole, more cared for, more capable and physically and mentally strong after mastectomy.

## **PHYSICAL**

**Feel/tactile quality:** soft so that it behaves like a natural breast and can ‘pass the hug test, smooth so that the surface texture is not apparent through clothing, lightweight. While not all women will want a lightweight prosthesis, there is a large contingent who do.

**Performance:** breathable, possibly absorbent

**Structure/form:** does not need to be solid; could be a lattice. Consider an adaptable form that is flexible, mouldable or can have weight and fullness added or removed from different parts, according to the wearer’s needs.

## VISUAL

Attitudes towards visual preferences will fall into one of three categories:

**Realism:** There is most definitely a place for realism. If even greater realism were affordably achievable, e.g. in terms of mirroring the other breast, matching skin-tone, creating a realistic nipple, there would be a market for this bespoke solution. Beige serves no women of any colour and women of colour are especially under-served. Not all women require a prosthesis to be hyper- or semi-realistic however: for some this is an undesirable quality.

**Expressive:** A proportion of women who wear a prosthesis respond favourably to alternative designs that are colourful, fun, expressive or fashionable. There is room to provide a range of designs to appeal to different aesthetic tastes. There is also openness among some to be involved in customising or personalising designs, although it should be noted that format, access, complexity and most crucially, timing of involvement, will factor into readiness to participate.

**Ambivalence:** Some women are ambivalent towards or unconcerned with the appearance of the prosthesis. Therefore, there is no reason for the EBP to simulate skin-tone in either texture or colour for this group, and resource can instead be channelled into making a more comfortable and better performing prosthesis. For practical reasons, it may be sensible to use colours which typically feature in lingerie (including fashion colours) so that the prosthesis remains visually unobtrusive.

## PSYCHOLOGICAL

**Social:** the participants in this project were looking for their prosthesis to help them fit in rather than stand out in a social context. The form and movement of the prosthesis should therefore mimic that of a natural breast as closely as possible. Additional consideration should be given to its appearance if it is exposed and inspiration can be taken from lingerie detailing to make the prosthesis look more like an item of clothing and therefore less conspicuous.

**Self-image:** for many women, the prosthesis plays a role in affirming femininity, whether in their own eyes or in the eyes of others. Additionally, it can enhance other aspects of identity and self-image such as sexiness or stylishness.

**Relationship to prosthesis:** responses towards the prosthesis vary from fondness or gratefulness to hatred. Consequently, due attention should be given in the design and presentation of the prosthesis to aid a positive relationship. One method of doing so is to explore what more the prosthesis can become – could it become more meaningful with the inclusion of a personalised element?

## EXPERIENTIAL

**Affordances:** A prosthesis can do more than provide shape under clothing. Since it must be present, consider how it can do more than just ‘sit there’: what else could it do and how could it make a woman feel better?

**Affordability:** the expense of prostheses and specialist lingerie is problematic for many women. Consider new ways to design or produce prostheses that could deliver a satisfactory product at a more purse-friendly price.

**Accessibility:** prostheses are typically accessed via a medical or retail pathway. For those wishing to avoid the expense of the retail pathway, there is much inconvenience and a return to a medical environment. How could the prosthesis be designed differently so that it no longer requires specialist fitting and can be adapted at home or otherwise made easy to buy the right size and shape without help?

#### 4.3.4 Designer's Guide to Re-imagining the EBP

The following prompts have arisen through my practice, in response to research, and are included here as matters for the designer to consider and creatively respond to:

- What new possibilities are created if the prosthesis no longer needs to be skin toned?
- What new structures could be created if the prosthesis no longer needs to be solid?
- How might the prosthesis design allow for customisation or personalisation?
- What designs might we create if the intention was to create something that made a woman feel pretty and feminine?
- How might we make the prosthesis beautiful and desirable?
- How might we make the prosthesis fun to interact with or incorporate humour?
- How might we incorporate a storage option into the prosthesis?
- What other secondary uses could a prosthesis have?
- What different designs might we create if the prosthesis was going to be seen in public? Consider communal changing rooms as well as social events.
- What products could we design that would have wider utility and appeal so that they are not a product just for women who have had a mastectomy?
- How might our designs help to break down taboos and celebrate bodily difference?
- What might a co-design approach to prosthesis design look like for us?



This guide to re-imagining is transferable to other applications. See appendix K for an adaptable, generic template).

## 4.4 Chapter conclusion

In this penultimate chapter, I synthesised insights gained through analysis of participant data and my creative practice. I provided six documents that can be used to consider women's preferences for EBP attributes, their emotional experiences during their cancer journey and how these both need to affect the processes used in the design of EBP.

## **CHAPTER 5: DISCUSSION & CONCLUSION**

## 5.1 Chapter introduction

In this chapter, I conclude the thesis with a distanced reflection on my practice-based research and its synthesis, a summary of what I have learned, a critical reflection on its contribution to knowledge and its wider significance, an acknowledgment of its limitations and the recommendations for further work that needs to be done.

If we are to design well *for*, we must design *with*. When we design with, we challenge designer bias, assumptions and agendas and instead create a conversational design process, resulting in a product that reflects user priorities. Reflective and generative activities can facilitate a collective re-imagining of an object and its personal, social and cultural meanings. Objects which have remained unchanged for decades may indicate deeply engrained cultural influence, a lack of diversity in the design team or an absence of users in the design process; further research is required to establish precise cause.

This research has combined a designer-researcher, non-users and users to suggest how a potentially harmful pattern of design and manufacture of EBP can be disrupted to create new possibilities.

## 5.2 Summary of learning and a note on limitations

Research data was predominantly gathered from white, middle-aged women who wear a prosthesis after mastectomy and are based in suburban or rural locations in South West England. The extent to which the various preferences specified in this research are specific to geography, culture, age, race, sexual-orientation, sex, gender or socioeconomics remains unclear. Literature on limb prostheses indicates that there are varying requirements in relation to gender (Hall & Orzada, 2015), (Resnik *et al.*, 2019), and whether the wearer lives in an individualistic or collectivist culture (Vlachaki, 2020), so there are grounds to assume these factors will influence the EBP requirements of individuals and groups whose demographic profile is different to participants in this research.

Conducting a multi-method qualitative practice-based research process as my first undertaking of this kind will inevitably result in limitations to the work. As a researcher-in-training and not working as part of a research team, I will doubtless have made decisions about design, methodology and analysis that a more experienced designer-researcher will easily spot and wish to question. I chose to combine multiple approaches to add richness and dimension to the research, but this risks the potential of becoming fractured and unclear. However, the previous synthesis chapter, and a recap of key learnings below, is intended now to gather any loose fragments and join them into a cohesive whole.

### 5.2.1 Women's experiences

This research questioned how a woman's self-image alters through her cancer journey. The data captured highlights a stark contrast between women's internal experience and how they are perceived by others (see appendix I, section 1). It justifies the selection of an empathic approach to design and the use of a multi-method qualitative methodology to capture multiple facets of women's experiences. Insights were then applied to the design of product prototypes and discursive exhibition objects to invite advancements respectively in EBP design and the discourse on EBP.

### 5.2.2 EBP aesthetics

The research identified that realism is not a universally desirable trait for the EBP and that there is appetite among some wearers for a prosthesis that can be made personally meaningful or expressive, or which resembles or references lingerie. Using a grounded theory approach iteratively to develop a set of adjectives or product attributes, participants used the card sorting method to indicate their preferences. Analysis of these preferences suggested not only directions for product development but distinct user personas. The benefits of expanding aesthetic options beyond the anatomically representational are found within literature on prosthetic limbs and evidenced in retail figures and strategies in the instance of sex toys. These precedents, along with a demonstrable openness among some participants in this research to consider and suggest alternative aesthetics for EBP, suggests that there are psychological and economic benefits to moving beyond realism with EBP.

### 5.2.3 Impact of EBP design

The prevalent aesthetics of external breast prostheses shape the physical and psychological experience of the wearer. Literature indicates that an alternative aesthetic to realism, based on wearer preferences, could bring psychological benefit. The physical experience of the wearer is impaired by issues with regulating temperature, moisture control and movement of the EBP. Through exploring alternative structures and materials, greater physical comfort and improved wearing experience could be provided: by moving beyond realism, it lifts several design limitations that currently impair the wearer experience.



#### 5.2.4 Design processes

The current commercial design process, by not including the wearer, misses a rich pool of expert opinion that could inform the development of prosthetic futures. This thesis challenges the status quo of external breast prosthesis design by showcasing alternatives which emerge when co-designing with wearers. The research outcomes demonstrate that the methodology of human-centred design - empathising and understanding user needs and desires - along with strategic use of co-design, speculative design and critical design, can drive improvements and innovations in product design. Consideration of the potential emotional affordances of the EBP yielded new aesthetic and symbolic possibilities (3.2.2, 3.8). Consequently, adaptation of design processes to encourage user involvement is recommended, as it has the potential to benefit all stakeholders.

## 5.3 Research value: contributions to knowledge and practice

I have taken insights and synthesised them into forms that could be disseminated.

These research outcomes have value to research and practice communities, and as such, may be considered contributions to knowledge.

Each of the first four contributions described below is of value to those working specifically in the design or research of EBP:

### **Contribution 1: Foundational design work for an alternative EBP (see 3.2.2)**

As a result of the foundational design work for an alternative EBP, there will be the following implications for wearers and designers/manufacturers of EBP:

#### **Significance for wearers**

Where concepts are applied, this will lead to improved comfort due to the non-solid form of the EBP and potential psychological benefit from altered aesthetics which may match the preferences of the wearer better than a realistic EBP. Additionally, the demonstration that some parts of the design and research community are motivated to seek out and apply user feedback may provide some comfort and hope.

#### **Significance for designers/manufacturers**

Designers and manufacturers may wish to respond to the challenge represented by this thesis and new physical structure for the EBP, applying their expertise to create new alternative EBPs themselves. Competition within this area will benefit the wearer by increasing consideration of user needs, choice and diversity. The

foundational design work has already been developed and applied by Boost Innovations Limited<sup>27</sup>, and more companies may be inspired to respond.

**Contribution 2: Framework for antidotal design** (see 4.3.2)

In addition to its applicability within EBP design and research domains, this second contribution provides transferable principles which will be of use generally to design practitioners and design researchers. It also provides a model which can be adapted by psychotherapists for creative therapeutic interventions with clients, echoing as it does the principles of gestalt.

**Contribution 3: Theories, models and guidelines for EBP design** (see chapter 4)

The set of theories, models and guidelines contained in chapter 4 can be tested and applied by EBP researchers and designers; they can also be assessed for their transferability within the wider field of prosthetics design. As outcomes of this research, they are yet to be applied; inevitably some refinement or adaptation may be required. I have detailed and synthesised my methods and practice so that I can provide designers and researchers with a starting point for further work.

**Contribution 4: Demonstrate the value of diversity and co-design within product design, especially for women's health and technology.**

This research provides an example of the value of co-design, both as a means of generating novel ideas and generating insights which can then be developed and applied in industry. The use of co-design in combination with design ethnography exposed previously overlooked issues with the existing product and revealed

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<sup>27</sup> [www.wewearboost.com](http://www.wewearboost.com)

potential for innovation in product development. Where design teams do not represent the diversity of the users of their products, opportunities to better serve users can be missed and the status quo is perpetuated: co-design and better diversity represent excellent antidotes. Concepts arising from the research have subsequently been developed and applied and now a new product exists in the marketplace and is being well-received by wearers.

The final two contributions are beneficial to scholars:

**Contribution 5: Highlighting that the aesthetic requirements of EBP differ to those of limb prostheses**

As indicated in the first chapter, little scholarly attention is yet to be given to the aesthetics of prosthetics in general, and the EBP in particular. This research reinforces the importance of aesthetics of prosthetics, both individually and culturally, that others such as Sansoni have cited, but adds new and additional dimension by focussing on the breast. As a prosthesis which is not publicly on display, considerations for external breast prosthesis design and its personal and social meaning differ from that of limb prostheses. Additionally, there is a gendered and identity-related component to this prosthesis which makes it different from limb prostheses worn by both sexes.

**Contribution 6: Highlighting gender-inequality within prosthetics research and design**

In addition to *elements* of this research providing value to design, therapeutic and research communities, the research *as a whole* represents a contribution to an under-represented area of research and practice. By documenting my exploration of

a concept conceived of by a woman, inspired by another woman, performed in collaboration with women, for the purposes of raising awareness of women's specific experiences and advocating for improved standards of design for women, I provide an impetus for feminist, design and engineering scholars to examine the cultural and practical reasons for this current knowledge gap.

## 5.4 Future Research and Practice

This practice-based research represents the first stage in examining the status quo of EBP design and how it can be challenged. There are many areas that would benefit from attention by researchers and practitioners, some of which I have identified below. While there will inevitably be some overlap between the research and practice, for simplicity, I have divided my recommendations into two separate areas, which should not be considered exhaustive:

### 5.4.1 Recommendations for researchers

- Establish the extent to which the various preferences specified in this research are specific to its participants (see 5.2)
- Attention should be given to how religion and cultural background affect women's experiences with breast cancer, mastectomy and prosthesis-wearing and how this influences the requirements of an EBP, for example, exploring how modest dressing impacts on prosthesis-wearing in Islamic communities.
- The specific experiences of women of colour must be explored. The main prosthesis providers in Western countries do not provide a range of skin tones, and where products for women of colour are available, they are limited to one or two options only. For those who find it hard to match their prosthesis to their skin-tone, a non-realistically coloured prosthesis, chosen on colour preference, could be a more inclusive alternative. However, this material solution does not nullify the need to address the racial bias present in current provision, nor the exploration of how lack of diversity and representation in skin tone of prostheses affects the self-image of women of colour.
- Explore the cultural impact of public exposure of EBP and similar products (e.g., the Breastflower)
- Gain understanding of the relationship between EBP and wellbeing through longitudinal quantitative and qualitative studies into the specific affect of the aesthetics of EBP.
- A critical discourse analysis of the product semantics (Krippendorff & Butter, 1984) of the EBP could aid the revision of how the EBP is represented and

understood in retail and medical environments with consequent positive benefits for the wearer.

- More generally, design researchers might want to explore the concept of grounded design, expanding its proposed usage beyond the domain of Information Systems to include multiple design research domains.



### 5.4.2 Recommendations for practitioners

The design of EBP packaging requires review. There is potential either to personalise packaging, or otherwise design it in such a way that it alters the user's interaction with it and the meanings she attributes to it.

- An investigation into more sustainable alternatives to the current silicone gel product which only survives around 2 years' of wear before it splits and needs replacement, has a limited shelf life and is not recyclable. A more durable material would reduce cost to the individual and health services and damage to the environment, as would devising an affordable on-demand method of EBP production.
- Explore how personalised elements might be integrated into EBP design and production processes.
- Test the summaries and recommendations for practice (see chapter 4) and report on the outcomes of their application. In particular, test the model of antidotal design of applicability to and beyond the EBP.

### 5.4.3 Personal intentions for future research and practice

At the heart of my practice is the desire to create and sustain wellbeing through the way people experience objects. I am interested to further explore how this desire fits within an ontological design framework.

I plan to continue:

- exploring how an interdisciplinary approach can be applied to disrupt or enrich standard practices of product design, user-research and user-centred design
- developing and applying the antidotal design model to areas beyond the EBP
- exploring the tension between empathy and automation, the emotional and the industrial – always advocating for the human user to gain and maintain prominence within the design process.

## 5.5 Concluding statement and call to action

*“If a joyful personalised prosthesis was available then perhaps more patients might reconsider undergoing what is without doubt invasive (and, dare I say it, costly) surgery.” - Bridget*

Re-imagining the EBP could play a small role in helping a woman move on after mastectomy, either because she is more comfortable and not aware of her prosthesis, or because looking at and handling her prosthesis becomes a joy and reflection of something meaningful and pleasing to her. Women’s wellbeing after mastectomy is lower in women who have not opted for reconstruction (NHS *et al.*, 2011), but if design processes are changed to yield more diverse options for EBP meaning and aesthetics, then perhaps when the NHS wellbeing audit is next conducted, we might see an improvement.

This research explores how it might be possible to address the negative aspects of some women’s experience in relation to her prosthesis by reframing the meaning of the prosthesis, changing its aesthetics and how it is viewed and described, and in so doing, aim to contribute towards a greater sense of satisfaction. If product design can be utilised to improve wellbeing and if an EBP can affordably be made both functional and beautiful, why would we not choose to make it so?

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<https://wewearboost.com/>

## **APPENDICES**

## **APPENDIX A**

### **RECRUITMENT CRITERIA**

Participants were a self-selecting group of adult females who had undergone a mastectomy; who own, or have owned, an external breast prosthesis, had not been diagnosed as having metastatic breast cancer, were recruited independently of any NHS service and who were interested in the research concept of a relationship between aesthetics, EBP and wellbeing. Agreeing that a prosthesis should/could be customised was not a requirement; indeed, participation to provide a counter opinion was encouraged from at least two participants to provide contrast to those who did like the idea.

Women were invited to share their experiences and desires relating to prosthesis and body image and identity while participating in creative activity and discussion. They were asked to share insights into what may be lacking and what they would like to see provided in the future for themselves and other women.

Supplementary interviews and two workshops were run with people who did not fit the above criteria, either in terms of gender identity, breast cancer experience or prosthesis use, so as to provide a wider range of perspectives.

For those participating in an in-person workshop, residence in or a willingness to travel to South West England (SW), was a requirement. A convenience sample was

therefore sought via 3 independent breast cancer (BC) support groups and public promotion of workshops to enable follow-on interactions:

## **RECRUITMENT METHODS**

### **Remote**

Set up a Facebook (FB) group that detailed my research project. Contacted group admin of 10 mastectomy groups on FB, asking to join, or if that was not appropriate, asking if they could post a link to my group. Approached a mix of groups, some with membership solely in the UK, and some comprised of mostly non-UK members, especially USA. Women were invited to join my group, respond to a few discussion threads and then to sign up for participation in the project. Put out a public post on FB to invite people to participate and signposting them to my FB group for details. Membership was 30 women, of which 8 signed consent forms to participate and were sent activity packs, of which 4 returned their packs.

### **Workshops**

Spoke to breast cancer nurses and local cancer support centre (Mustard Tree) for insights into where I might recruit from, aiming to find any groups not affiliated with the NHS. Between recommendations, a Macmillan regional listings page and support from a locally based FB support group moderator of a national group, I was able to connect me to a group that was not publicly visible which I was then able to visit in person. Overall, I identified 3 groups in SW that met my criteria. Breast cancer support group leader informed eligible women about the research project and invited me to be the guest speak at one of their monthly meetings. Information sheets and

consent forms were taken to the meeting and any women interested in considering how the aesthetics of EBP might impact wellbeing contacted the researcher to enquire further, and returned a consent form. These women were invited to a follow-up workshop. The breast cancer support group leader or lead contact also circulated details of the workshop/workshop publicity so that anyone who had not engaged so far would have the opportunity to participate.

## **Interviews**

Contacted Coppafeel charity to say I was looking to reach young women who had had a mastectomy and wore a prosthesis and would it be possible for them to promote the interview opportunity. A charity rep circulated the opportunity and 4 Boobettes from around the UK contacted me to be interviewed. The intention was to gather a counterpoint to the views of older women I had thus far engaged and who felt that the concept might be better suited to a younger audience. Also to provide insights that would inform workshop content.

Boobettes are young women who have had breast cancer and whose role it is to raise awareness, typically with young audiences. The rationale was that as women used to and comfortable discussing their experiences, deeper insights might be possible from interview than asking someone who may not have reflected on all aspects of their experience to date or who might not be comfortable with answering questions.

## **APPENDIX B**

### **CHOICES I MADE, EVIDENCING A FEMINIST/INCLUSIVE PHILOSOPHY**

- Show, not exhibition (inclusive language, egalitarian)
- Opening, not private view (non-exclusive)
- Curated, not authored (acknowledging collaboration)
- Co-design not solo design (collaborative)
- Providing power to participants as much as possible
  - Mostly visiting groups in their usual group setting; in the case of Bosom Pals, their preferred setting was at the University for transport reasons/convenience
  - group select dates and times of the workshop
  - Group offered chance to define follow on workshop content
  - Remote activities/design probes could be completed in the participants own space, at a time/times to suit them
- Show structured to tell story of thesis and take people on a journey that reflects the research and practice journey – ie starting with empathy
- Variety of methods to provide optimal opportunities for engagement at different levels of creative competence and confidence
- Cabaret/circle, not proscenium arch seating formats
- Speaking while sat during workshops unless needed to stand briefly for better visibility/to command attention at the start of the workshop
- Aiming not only to examine women's experiences but also social change around gender inequality
- Flexible approach to avoid responses being limited by researcher's agenda

- Iterative process, methods change in response to participants' comments – not having a fixed research/personal agenda
- Interview questions were semi-structured and the researcher ensured she followed directions determined by interviewee as well as asking about the areas she had pre-determined.
- Steering group were formed and consulted to check out preliminary strands of enquiry were on the right track.
- At its heart the project sought to benefit women. Pushing for alternative aesthetics so that those who currently feel under-served could be acknowledged. The project also sought to benefit women by contributing to an R&D phase of a commercial product by female founders, based on a mix of solo practice (as a woman), Sam & Sue Jackman's ideas and the learnings that arose from female research participants.
- Staged an exhibition, intended as an opportunity to formally present the research at this stage and then invite comment. Comment was not formally sought (had thought about doing a survey, could have done a focus group or other event). This was partially down to personal circumstances at the time and partially because at this point I did not fully understand the importance of providing that opportunity to feedback – I was framing it as a more self-serving exercise in terms of providing feedback on the exhibition, not on the research – and this did not sit right with me or seem important so I did not go through with it. Looking back, I should have done something to continue the dialogue.
- Sent out design guidelines after secondary analysis of the data and invited feedback as a form of 'member checking' or validation.

- Sent out design guidelines as an ethical/political act of returning the research to participants, to whom it belongs – allows women to see their views reflected, learn of others views and understand that they are not alone and are being listened to.
- Multi method approach to ensure I was able to gain broader understanding of lived experience



## APPENDIX C

### Informed Consent Form

**Project:** Increasing Wellbeing Levels in Women Post Mastectomy: The Role of Aesthetics and Co-Creation in External Breast Prosthesis Design

#### Project contact details:

Researcher: Rosie Brave

Telephone: [REDACTED]

E-mail: [rosie.brave@postgrad.plymouth.ac.uk](mailto:rosie.brave@postgrad.plymouth.ac.uk)

#### Project Summary

The focus of this project is how wellbeing levels in women post mastectomy may be increased by participating in the design of a personal decorative breast prostheses. For a full summary, see the Research Information Sheet.

By signing below, I confirm that I have read and understood the Information Research Sheet provided and, in particular, have noted that:

- I understand that my involvement in this research will include a design exercise involving drawing and 3D modelling, group and individual discussion, an exhibition event and may include a verbal or written interview.
- I have had any questions answered to my satisfaction;
- I understand that there will be no direct benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary
- I understand that if I have any additional questions I can contact the researcher
- I understand that I am free to withdraw at any time, without explanation or penalty
- I understand that any information from this research project and on its participants will be held securely, in line with the Data Protection Act 1988.
- I understand that if I am dissatisfied with the way the research is conducted I can contact the researcher in the first instance: Rosie Brave, School of Art, Design and Architecture, Plymouth

University, [rosie.brave@postgrad.plymouth.ac.uk](mailto:rosie.brave@postgrad.plymouth.ac.uk), (0)7453 267383, or her supervisor, Mike Phillips, Professor of Interdisciplinary Arts, Plymouth University, [M.Phillips@plymouth.ac.uk](mailto:M.Phillips@plymouth.ac.uk) +44 (0)1752 586262

☐ I agree to participate in the project.

☐ I give my consent for the data to be used in reports, presentations, publications, creative media, websites and exhibitions connected to the '*Increasing Wellbeing Levels in Women Post Mastectomy: The Role of Aesthetics and Co-Creation in External Breast Prosthesis Design*' research project.

☐ I give permission for my name to be identified in this research project.

☐ I would like my name to be anonymised in this research project.

☐ I give permission for non-commercial use and reproduction of the designs I produce in the codesign workshop.

☐ I grant permission for the researcher or her assistant(s) to capture photographic images and audio or video recordings during our face-to-face contact for the purposes of research analysis and documentation.

☐ I grant permission for photographic images and video or audio clips in which I feature to be shown to public audiences (e.g. exhibition, conferences, online).

☐ I grant permission to be contacted directly by the researcher for purposes of clarifying information in relation to the research. I understand my details will not be passed on to a third party.

My email address is:

.....

☐ I grant permission for my age to be recorded in research outputs.

My date of birth is: .....

|           |  |
|-----------|--|
| Name      |  |
| Signature |  |
| Date      |  |

## **APPENDIX D**

### **BECOMING: 10 NEW POSSIBILITIES FOR EBP**

#### **Introduction**

The work shown below represents conversations, ideas and designs that occurred during a variety of interventions, from creative workshops to remote activity packs. While my initial intention was to help each research participant to create her own unique prosthesis design, it became apparent that not everyone wanted this, and that some women wanted similar things. A more effective way to bring these ideas together then, rather than a direct translation or interpretation of women's stated desires, was to synthesise some of the key elements in what participants expressed they want and use the exhibition as a vehicle for telling these different stories and showcasing the diversity of aesthetics and potential psychological benefit that alternative or expressive prostheses can offer.

## **1. It doesn't have to be beige or solid**

### COLOUR

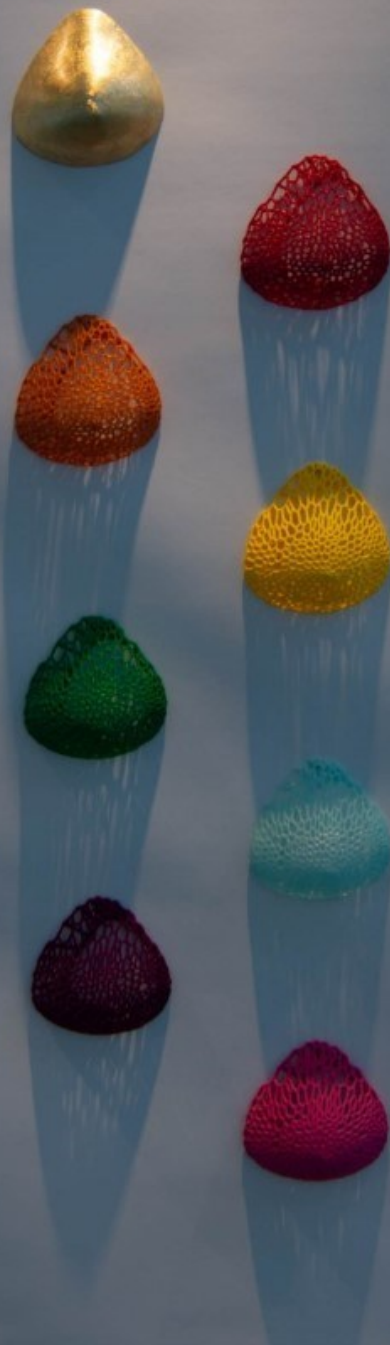
Design: Rosie Brave

This collection of coloured and open-structure models explores the idea that a breast prosthesis need be neither beige in colour nor solid in form.

The starting point for this research project was that external breast prostheses did not need to be beige. Indeed, the idea that they could be the favourite colour of the wearer and used to express some part of the wearer's identity was the impetus for this research. What was not known until I started working with groups of women and doing design experimentation in response to their comments, was that the external breast prosthesis did not need to be solid.

The initial making objective was to find ways to transfer print and pattern on to a silicone gel prosthesis. However, by making the pattern part of the prosthesis' structure, not only does it create a visually interesting object, moved farther from the realistic aesthetic of the current product, but it also addresses the commonly held complaints of heaviness and sweatiness. By removing volume from the object, it becomes lighter and by allowing air to circulate through the openings within the object, it becomes cooler to wear.

*It doesn't have to  
be beige or solid!*



## **2. It can become inspirational and meaningful**

### **ELEPHANT**

Design: Gita M. & Rosie Brave

Gita completed a research pack and sketched an elephant. She enclosed a letter on patterned notepaper and this forms the decorative background for the elephant design.

Gita's inspiration is rooted in her Indian heritage. The design is to remind her of the Hindu god Ganesh and the qualities of courage, wisdom and strength. She says: "Like the elephant, you will never forget the experiences you have been through – but you can get through and you are stronger than you think you are."

A prosthesis is potentially always going to remind its owner of the trauma of breast cancer. However, by choosing one's own design, one linked to personal and cultural identity and full of symbolic meaning, the prosthesis can become something inspirational and personally meaningful.

The current prosthesis seeks to emulate a breast but because it is not made of living tissue and is not connected to the body, it can never evoke the same response or carry the same meaning. Some women feel quite dispassionate about their prosthesis, calling it "a lump of rubber"; its materiality is synonymous with its failure to embody what it represents.

However, if there is no attempt to simulate visual reality, then instead, the prosthesis can be

viewed as a canvas. Adding and removing the prosthesis to the bra or to the body is part of the daily ritual of dressing. This regularity invites the opportunity to use the canvas of the prosthesis surface to carry a message or image that would benefit the wearer from seeing regularly.

In the same way that some people wear prayer beads, or jewellery that contains symbols of their faith, the visual contact with the image contained on the prosthesis can provide connection to the wearer's values and reinforce the message and meaning contained within. If someone has a daily practice of using prayers, mantras or affirmations, the prosthesis could provide a visual prompt or aide to this routine.



*It can become  
inspirational &  
meaningful*



### **3. It can become a reminder of what I care about**

#### **CHINA PATTERN**

Design: Angela M., Rosie Brave and Hebbby Anatholia

Illustration: Hebbby Anatholia

Angela provided photographs of the things that make her happy. Her two dogs and the flowers in her garden. Angela appreciates delicate designs, so this bespoke china pattern was created just for her.

When decorated with imagery that the wearer supplies, the prosthesis can become a reminder of what the wearer cares about.

In asking participants to take photographs and keep a journal, I was provided insight into elements of their lives they particularly valued. By focusing habitually on positive thoughts and memories, the brain's neurochemistry can be altered, and individuals build a habit of paying attention to things that make them feel good.

While the prosthesis may provide a physical signal that cancer has been removed from the body, it is also a reminder that the breast has been removed. By habitually drawing the mind back to cancer, it can play into existing anxieties around reoccurrence of cancer.

If the prosthesis can provide a canvas for imagery or text that conveys what the wearer holds most dearly, then it can serve as a reminder to treasure and focus on the parts of life that bring pleasure. Additionally, with the location of the prosthesis being close to the heart,

it provides a symbolic layer to the use of the prosthesis; someone is keeping what they care about close to their heart.

This is represented here in bone china – to highlight the fragility of life and a reminder to handle it carefully and with respect. While this is not suggested as a suitable material for a wearable prosthesis, it hopefully conveys a deeper level of meaning about the need to treasure life and the things people hold most dear.

*It can become  
a reminder of  
what I care about*



#### **4. It can become comforting and affirming**

I LOVE YOU STILL


Design: Nita G. & Rosie Brave

This design captures a phrase provided by Nita that her late husband would often say to her.

Regular interaction with a personally meaningful phrase could have an affirmative and comforting effect. Daily interaction with a prosthesis can be a reminder of what is lost or missing but using a personally significant and positive phrase and a calming colour, the prosthesis can become something comforting and affirming.

After the trauma of breast cancer, and with an altered body, insecurities about sexuality and feminine identity can plague a woman. Some partners navigate this beautifully, affirming their partner's attractiveness and highlighting their other physical assets such as legs and buttocks. For those who struggle to accept complements, having an affirming and comforting message from their partner as part of the prosthesis, which they interact with daily, could help embed this message. Even for those for whom this is not an issue, the possibility of including a message from a loved one provides the possibility to make the prosthesis something more special and intimate, like a photograph or engraved message in a locket. And for those who want to remember a loved one who is no longer alive, this can work especially well, as a private memento that does not need to be seen by anyone else.

*It can become  
comforting & affirming*



I LOVE YOU STILL -  
AND ALWAYS WILL

## 5. It can become pretty and feminine

### PERFECT ROSE

Design: Elizabeth B., Tereza Chytilova, Finlay McKinnon, & Rosie Brave

Glass: Lucy Swift

Elizabeth received a design kit by post and provided two photographs to Rosie. In her notes to explain the photographs, she says: “The sparkly heart was something I gave to my eldest daughter when she got married, it is very precious to me.” and “The second photo is of the most enjoyable kind, roses, it cheers me so if one could be as 'perfect' as those.”

The romantic imagery and idea of the link between perfection and roses inspired the title Perfect Rose. Design students, Tereza and Finlay responded to the brief of Perfect Rose, studying how rose petal formation conforms to the Golden Ratio or a perfect spiral. This inspired the swirling coloration in the glass, created by adding broken pieces of a glass sculpture, fittingly formerly a heart.

When taking cues from romantic imagery, the prosthesis can become pretty and feminine. While what might be considered “pretty” or “feminine” is rather subjective, if the prosthesis can embody the wearer’s definition of this – assuming that is desirable to them – then it helps mitigate some people’s response to the prosthesis in its current form, which some describe as ugly.

Sue described hers as a beige blancmange – not an appetising image – and named it “Franken-boob”, after Shelley’s *Frankenstein’s* monster. A thing, then, of horror, to be

pitied, feared or avoided.

However, if the prosthesis was pleasing to look at, desirable even, and created positive feelings in the wearer, then this could inspire her to have a more complete view of herself.

Many of the women I spoke to complained about the lack of pretty or feminine post mastectomy lingerie, so this is where these words came from. I took inspiration from the traditionally romantic imagery of roses. I wanted something that encompassed the idea of beauty and romance and created a design brief, but I did not want to be too prescriptive. However, I did suggest it could include scent to make it more sensual, which is how we arrived at the idea of it being like a vase.

Of course, glass is not a practical wearable solution but by providing some lateral imagery, it may inspire other innovations. The addition of essential oils to provide different fragrances is something that has been variously suggested during workshops, and depending on the material of the prosthesis, and how the scent is contained and released, could be incorporated into a prosthesis, so that the heat of the body will activate the release of scent, in the same way as perfume placed directly on the skin.

The glass form has a slit in it. While this was viewed as an error by the maker, the designer and I were delighted. The initial plan had been to create vase with an aperture at the top but there was insufficient time to make a two-part mould. When Tereza and I saw the split, we knew instantly we could insert a rose into this, and it would perform the same function. Additionally, there was additional resonance with Fine Art imagery of the wound in Jesus'



side when he is pierced by a spear on the cross. Likewise, the opening within the form looks not dissimilar to the opening that is made in some breast surgeries. That a beautiful rose rises from this wound felt quite poetic, again, drawing parallel with Christ's resurrection. That an object of beauty is made from broken glass – in this case, a broken heart – adds further poetry to the piece and communicates a hopeful message that healing and beauty can come from something painful. Likewise, the breast form is not whole, and neither is the body, but this piece embodies the notion that a prosthesis can become something different, a new way of being beautiful that a complete breast or body does not offer.

*It can become  
pretty & feminine*



## **6. It can become beautiful and desirable**

### **MERMAID**

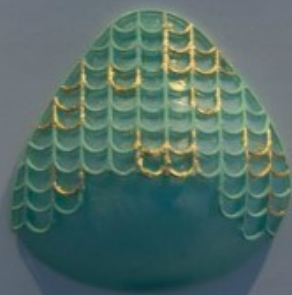
Design: Rachel P. & Rosie Brave

The irresistible allure of sirens and popularity of mermaids provide a suitable connection to the theme of this design. The loss of one or both breasts can impact sexual relationships and gender identity. Many women struggle to feel sexy or feminine after mastectomy. A beige approximation at Caucasian skin-tone, with a wrinkled skin and wobbly jelly-like feel does little to increase anyone's desirability.

This design is inspired by the sketches Rachel produced in a prosthesis design workshop. The colours are reminiscent of water and the shimmer of scales on a mermaid's tail.

With the positive associations of the imagery and delicate design, the prosthesis can become something beautiful and desirable.

*It can become  
beautiful &  
desirable*



## **7. It can become fun and expressive**

### **DISCO BOOB**

Design: Samantha Jackman, Izzy Tulloch, Henry Carr & Rosie Brave

Electronics: Henry Carr

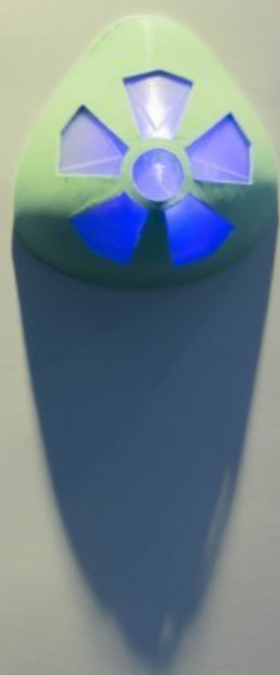
The concept for the Disco Boob arose during a speculative design workshop on 14 December 2017 at University of Plymouth. The Disco Boob will flash its lights in response to sound, and in this case, with a dance beat.

In most cultures it remains taboo to bare a breast in public. With a prosthesis being a false breast, there is perhaps even more reason to keep it hidden. But in a more open-minded, expressive and accepting environment of the club scene, might it be possible to show off one's prosthesis?

There is a growing trend for women to go without a prosthesis. Going flat or having a "mono-boob" is a clear challenge to society's expectations. Another way to challenge this, and add some humour into the bargain, is with a prosthesis that is worn to be seen.

For the woman who wants to use her prosthesis as a talking point and make a statement, the prosthesis can become fun and expressive.

*It can become  
fun & expressive*



## **8. It can become useful and give me an advantage**

### **ZIPPY TIT**

Design: Bridget P. & Rosie Brave

It is a little-known fact that women often use their bra to carry mobile telephones, tissues and money. Taking this concept one step further, Bridget created the concept of the Zippy Tit, a way of storing items in the prosthesis.

Inspired by Bridget's mood board fabrics in bold, bright colours, and her account of others describing her as a "superwoman", this design combines a practical storage option featuring top access, with a superhero colour palette. The construction is reminiscent of Wonder Woman's armour. With the addition of storage in a place that most women would have a breast, the prosthesis can become useful and give the wearer an advantage.

Currently, an external breast prosthesis is a non-functional prosthesis or cosmesis. However, if it were afforded storage capability it could begin to have some functionality. Design workshops yielded several novel solutions for functional prostheses from wearers, including radios, heart monitors and cooling devices. There is certainly – literally - room for innovation when it comes to the prosthetic breast, it just requires us to move beyond the paradigm of realism first.

*It can become  
useful & give me  
an advantage*





## **9. It can become OK for it to be seen in public**

### **SPARKLE**

Design: Hilary C.

Hilary proposed a design for herself that was white with silver sparkle and where there was “no need to hide it”. Women who wear a prosthesis and use open changing rooms at public swimming pools, may find themselves being asked about their prosthesis.

Seeing a detached prosthetic body part is an unfamiliar and potentially disturbing sight for many (Mori, 1970). Questions or comments follow that may be unwelcome. A prosthesis that does not strive for realism can avoid these interventions; it will not be immediately obvious what the object is. This can both protect the wearer and provide a springboard for conversation that can allow the wearer to raise awareness about mastectomy as well as communicate something of her identity and design style at the same time. The precedent for the latter already exists with those who use colourful limb prosthesis covers; it invites conversations and draws people in instead of turning them away.

If abandoning realism, the prosthesis can become OK to be seen in public.

*It can become  
OK for it to be  
seen in public*



## **10. It can become something others want to wear**

### **TATTOO TAPE**

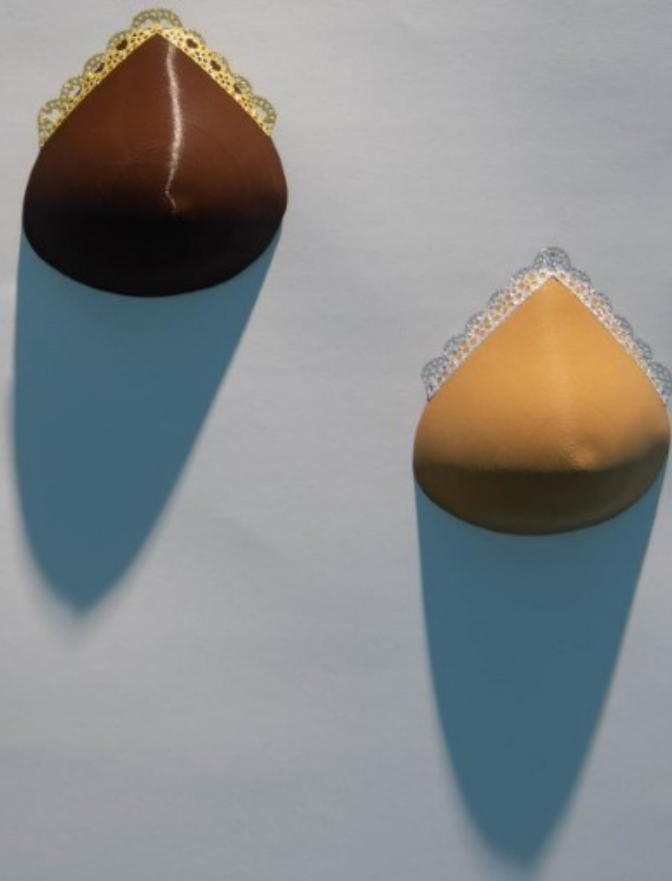
Design: Heather S.

Heather completed a research pack and sketched her idea of Tattoo Tape which mimics a tattoo. For use on the join between the skin and a contact prosthesis (one that adheres directly to the chest wall), Heather suggested that the tape “can be worn on breasts by anyone – this would mean no-one would know if it was a fashion accessory or for a prosthesis.”

With the concept of Tattoo Tape, a prosthesis accessory can become something others want to wear.

Jewellery-style tattoo transfers have been fashionable in recent years, and the concept of a product that can bridge communities, one that reduces stigma, and even flips it, is exciting. Like the child who is the envy of his friends because of his superhero arm, women who do not need to wear a tape to cover the join between prosthesis and skin might want to start wearing it to decorate and emphasise their breasts. Like the prosthesis that is designed to be seen, tattoo tape, being a new thing, will encourage curiosity, compliments and conversation.

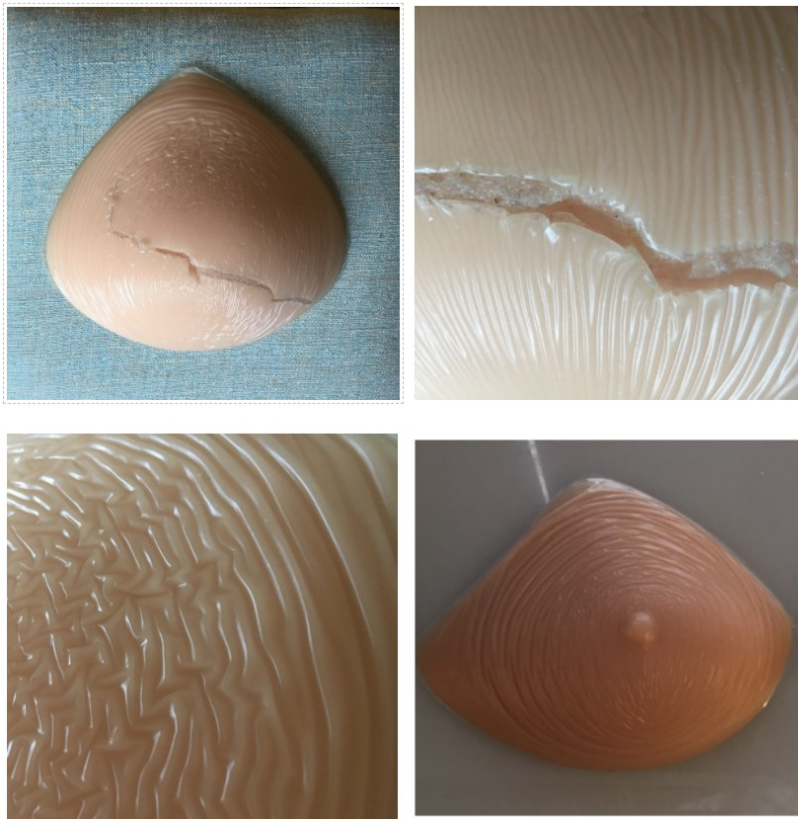
*It can become  
something others  
want to wear*



## Conclusion - Spreading the word

With the involvement of both research participants and designer-makers, I intended to demonstrate the concept of co-design in practice. The message was intended both for the public and for designers, to instill awareness of the end-user, hoping this might translate into their future practice and conversations with peers. In this way, how something is designed as well as what is designed, is a form of activism. Showcasing this publicly and within educational environments is important to disseminate the message.

By framing the different potentials of what a prosthesis could become, I intended to raise consciousness in prosthesis wearers to demand more choice and to be aware of how design aesthetics and the structures of the design and manufacturing industry can ultimately affect how they feel about themselves.



## APPENDIX E

### SAMPLE RESEARCH PROTOCOL

**Name of Researcher:** Rosie Brave

**Title of Research:** Increasing Wellbeing Levels in Women Post Mastectomy: The Role of Aesthetics and Co-Creation in External Breast Prosthesis Design

### INTERVIEW QUESTIONS

#### Surgery

1. How long ago was your surgery?
2. Did you have a single or double mastectomy?
3. What were your reasons for opting for an external prosthesis?
4. Was your surgery preventative? If so, how did this affect your decision about using a prosthesis?

#### Prosthesis

5. What are the good and less good aspects of wearing a prosthesis?
6. How often and when do you wear your prosthesis?
  - a. If not often, what reasons are there for why you don't wear your prosthesis?
  - b. What would need to change for you to wear your prosthesis more?
7. What qualities/attributes are you looking for in a prosthesis?
8. What general improvements could be made to the prosthesis?  
*Thinking about how it feels when you handle it, how it feels when you wear it and how its appearance could be improved.*
9. Are there any changes you would want that might affect how others respond to your prosthesis (when worn, or when your prosthesis is on the side at home or at the swimming pool).
10. What does the prosthesis mean to you? (*Eg, do you see it as a body part, an accessory, etc*)

## Alternative Prosthesis

I have met a group of older women who I presented the idea of a customisable prosthesis to. I showed them images of tattoos over mastectomy scars as a way of women telling new stories about their experiences and identities. I showed them 3D prototype models for alternative prostheses. They felt that the idea was more suitable to younger women. They felt it was important for it look pretty and feminine. They were positive about a lightweight design that allowed air to circulate.

11. What do you think about the idea of making the prosthesis feel more feminine or pretty?
12. If you were presented with the option of a *customisable* prosthesis would you consider this?  
(*eg, you could choose colour or decorative elements*)
13. If you were able to customise or personalise your prosthesis, how much involvement would you like? Eg choose colour, choose pattern, design pattern, collaborate with a designer...
14. If it were affordable, would you consider owning more than one, like with underwear or scarves that you might choose different ones according to your mood?
15. Would a design created by a fashion brand or artist be interesting to you?
16. What do you think of the idea of integrating a prosthesis (probably a decorated one) into a garment? Perhaps a lace prosthesis into a lace top for example?

## APPENDIX F

### SAMPLE INTERVIEW TRANSCRIPT/SUMMARY

#### Participant 1G: Interview Notes (21 August 2018)

- 2005, I was nearly 47
- Surgeon mentioned reconstruction but after I had treatment I had a blood clot which can be a side affect of chemotherapy. I was offered it but I wasn't contemplating it but the option was taken away
- I asked the surgeon if he would take the other one off but he said 'No, we don't do that'.
- The lesser of two evils
- (int) Was it something you kept private?
- "Oh no, everyone could see the scar if they wanted to.
- 1:40 (int) what did it mean to you to lose a breast?
- Because of my age not an issue
- It's just one of those things, you just cope with it
- You are in a bit of a blur really...it was fairly fast
- 3:37 not much time to process but probably just as well really
- 4:10 because I was 47 I was sort of like early stages of the menopause so I wasn't terribly concerned about it really....it was a long time ago and a lot of things have changed since I've had surgery...I think treatment is a lot more specialised....
- 5:00 when I heard they didn't take my other one off I was a bit concerned about going back to work I was told to go to [local town] for bras – there was no internet – they definitely didn't stock them in Marks & Spencer's or anything like that. You've got 6 weeks where you're told not to drive
- 5:55 Scar is tender and you go back (after 6 weeks) and are given this prosthesis which weighs a tonne and I did honestly try and wear it for a while but it was a really hot summer and it was so heavy and you are quite sore or tender and every time I bent over it fell out!
- 6:23 and bras are quite expensive in those days – they've come down a lot – I didn't get any help because I'm technically self-employed and I was trundling off to hospital so I just didn't bother. I didn't wear the false boob they gave me. And people are too polite. Everyone in the village knew, it was just one of those things – the advantage of living in a small village is everybody knows and nobody cares.
- 7:30 there were quite a few young women who had young families...they were very scared. In a way it was easier for me because [my daughter] was grown up so it didn't have that emotional impact
- 8:35 I didn't wear the wig either because again, the summer, it was just so hot. I mean you pick and choose, around the village or in the house I wouldn't bother but if you went out you did, and when it got cooler I just wore a hat....but I recommend the wig trying on, that was fantastic.
- 9:39 I cannot imagine what it was like having young children – the cancers are so aggressive – it was easier being older and if you've got to deal with the aftermath
- 10:57 I think while you're having treatment – I think it's only after that you worry about body image and such – it was quite fraught really
- 12:00 re: body image, dressing smart, make up, comparing her attitude to someone who cares about that stuff



- 12:30 re: about her sister who dressed up, wore wigs regularly etc
- 13:00 because I was 47 and I'd already had a couple of years of the menopause and your body shape changes and I don't think it makes that much of an impact at that age, at my age, but then it depends – I'm not a business woman. I don't need to present a smart, complete, what a person expects to see in a successful woman – I was just normal.
- 14:00 re: swimming – I was getting changed, I mean obviously you don't flaunt it, especially in front of the kids...I'd put my towel around me and was trying to help her....the towel slipped and she looked at me and then she looked at [intake of breath] and then she maybe thought maybe it wouldn't be appropriate to ask – you can see on children's faces, they're so expressive ...I could tell she was itching to ask... they'd had a teacher at school who had had breast cancer and she told you to change in the cubicles, in front of the children....kids don't get upset about things like that – they're more likely to be upset about things they see that aren't explained rather than things that are a bit weird. (16:39) I thought 'yeah, I'm not going to do that'
- 17:35 expectation on you to raise funds...cancer is just something I had, it's not my big life adventure
- 18:10 it's a bit like TB in the old days – it was serious and now it isn't. You take medicine. You don't go around raising money for TB charities
- 18:54 everyone's had breast cancer
  - 19:00 back when I was a kid, the ones that went in the paper were the ones that were going to live. Now the ones that go in the paper are the ones who are going to die because treatment has got better and good news doesn't make papers.
- 21:30 (Int) what was your initial response to the prosthesis, to the thing itself?
- (laughs) well I threw it round the room several times, didn't I? (laughs) mostly at young men who didn't know what was coming (laughs)
- 21:49 the trouble is it's what's included at the time and while you're going through treatment you don't know what's around – it's really since the internet that there's more choice – and now if I go out I wear one of those foam things because it's lighter but it's still hot and I don't do it a lot – it doesn't feel horrible but it doesn't feel right, yeah?
- 22:53 I think, because they all try to imitate a real one, it's stupid. I think the best thing to do is just sort of brazen it out but that, that is my opinion ...I've seen some of the things, the false boobs. There's no point pretending you've got a real one if you haven't so why not sort of flash it around with a sparkly one or a purple one or whatever, which makes much more sense to me.
- (Daughter) a bit like your sister and her wigs – she's into self-expression – she's been doing it for years.
- 23:24 There's no point to me in trying to make a false boob look like a boob. It's there to fill out the other side of your clothes in the nicest way possible, and the NHS do not do that, in my opinion.
- 24 But then I've talked to some women my age who had smaller boobs and they were perfectly happy. They had, you know, the proper bras and the one for swimming and stuff...but they were all quite well to do I think, and then the body image comes into it...I mean they probably had quite successful husbands so they had to present a society...presentable front.
- 25:13 It's amazing, I had quite a few men come up to me... they hadn't asked their wives and their wives hadn't shown them (shows her scars to people) - it's only a scar -

- 26:28 when I went to the surgeon and asked him to take the other one of and he said 'oh we don't do that – what would your husband say?' and I said 'it's not my husband's boob' and he went 'yeah, but we still don't do it'.
- (int) it's interesting who gets a say
- Yeah, and why aren't there more women doing breast cancer [surgery] because then you could say to a woman 'look, I'm 47, I'm not going to have children any more. My breasts have done my job, they have raised my daughter. Why would I want one?...they have different connotations for a boob. Men are quite happy to remove your womb so why aren't they happy to take off a redundant breast? Especially at my age, I wasn't going to have any more children, I'd been sterilised.
- 28:00 (Daughter) ...procedure. It's not always about the connotations. They are worried that in the day and age where everyone's feelings get hurt and everyone gets sued now and then that they have to give you the options to go back – retain the figure that you've lost as much as possible.
- 29:15 (int) what was the link between your breasts and femininity?
- Like I said, nothing now, or nothing then, they'd done their job....I've never been sort of like aware in myself that I equated breasts with my femininity. My boobs grew quite quickly when I was a teenager so you'd get all the boys and that's quite nice as a teenager but not at 47!
- 30:48 (int) so for you, is there any relationship between a prosthesis and femininity?
- Oh god no, none at all! I'll go into [nearest city], you just forget to put it in. If I'm going somewhere new or posh or anything just to conform to society's expectations that a woman should have two breasts but if I'm out and about shopping, very often, most of the time I forget, or don't bother, because it's just something that's there and actually having a false boob is so much hassle.
- 32:00 I've taken [grandchild] swimming without one – nobody says anything, they're all too polite
- 32:24 (int) Any changes?
- Yeah, if it was comfortable to wear and if it was – um – I mean I'm not against wearing one per se but it's got to be comfortable and interchangeable. I mean there's no point me having half a dozen boobs at home, but if I had one that did a multitude of tasks then that would be fine...nowadays the technology is here, there's no reason why there has to be one for one thing and one for another.
- 33:54 Well I suppose you were concerned about it and you weren't confident about it, having one would increase your confidence. Having the treatment afterwards – having the breast off is the easy bit – the treatment after is quite prolonged. If you're someone who appearance matters to it would give you a confidence boost – I mean, I think they're a good idea but they need to be tweaked – a lot – for me to wear it permanently
- 35 It has to be less hot – my scar is fine now – you have to give it a bang for it to hurt - it's not the same sort of feeling as when it's first – when you have surgery first, you need to have something that is light and cool and easy to wear. It doesn't necessarily have to be multicoloured or sparkly but it has to be nice. I mean, you've seen my NHS one, it's not exactly inspiring is it? She's shaking her head for the recorder (laughs) and if you've come out of surgery and you're still waiting to hear you're ok, having this lump of blancmange (laughs) is not going to help. And the other thing is you can't wear a bra for a first few weeks – I found I was too sore – it depends how big your scar is
- 37 (int) what do you see the prosthesis as? How would you describe it?

- Well it's definitely an accessory, but I think, to me, it's just a sort of like a statement that you're conforming to what society expects you to have. It's not – I mean it's not – if – it's a bit like if people lose an arm or a leg and puts on a false one – it doesn't work as well. It does help you to get around but it's not like the real thing, so when you're at home you probably don't bother to use it, or when you're comfortable in social situations you probably don't bother to use it
- 38:28 I was shopping...and there was this girl younger than [grandchild] and she had this beautiful dress on and she had two blades and I thought 'yes!'. Rather than have two heavy false legs that you have to sort of swing your legs and walk, she was bouncing! I noticed her because she had this beautiful dress on and because she was bouncing. And I thought 'why is she bouncing?' and it's because she had blades ...it was lovely, and that to me, is what a prosthesis should be: an enhancement rather than ...'oh well, you haven't got one so we'll give you this one and it's heavy and it's beige but you know, it'll stop people looking at you'
- It's not even breast colour. If you're tanned, if you go out and get a tan you can't wear a low cut dress because this is the wrong colour. It's just stupid (laughs)
- 40:20 You can choose – everyone's different – you can choose what colour you want to wear that day, I mean you can wear beige if you want to, but also if you were feeling nice and bright then you can choose a pink one or an orange one. It should be like the blades, an enhancement. Yes, I haven't got a breast but I've got this – and it's better!
- 41 (int) what do you think of making the prosthesis more feminine?
- That's hard to answer....(daughter and interviewee talk about not being girly girls/prettiness or femininity doesn't resonate –different for everyone)
- 42:41 For me functionality comes first, but if it can be functional and – cool – that would be great because like I say, I'm 60 now, feminine things are (laughs) I'm just not worried about it any more, as such
- (Int) but you're still looking to have fun and express yourself
- Yes, well now – I've done the kids, and I've nearly done the grand[child] – and now, it's me – I'm not exactly feminine – I mean I can put a skirt on and look alright but I'd rather be out mowing the lawn. But the girly girls who do want to be feminine need to have the pretty little things and if they can get their nails done and have a boob to match -
- (int) if you had the option to have a customisable prosthesis, is that something you would consider
- Yes, yeah, definitely. Quite honestly, the NHS ones if they were easier to wear, I mean you know, back when I had it done, beige was fine because that was all you knew but times have moved on and people have moved on, it would be nice to have a choice. You could have something fairly plain for work – you need something compatible with your life.
- It falls out or it slips round.

**Notes are a blend of approximate and verbatim transcription, allowing me to capture key points and return to relevant sections to do a full verbatim transcription if necessary.**

## APPENDIX G

### **Social and Personal Meanings: Discourses of completeness**

In marketing prosthetic limbs, companies choose positive words and phrases that indicate a clear psychological benefit and acknowledge the power of design to reflect the individual: “empowering”, “inspiring”, “heal you mentally and physically”, “unique”, “boosts...self-esteem”. They tend to defy the notion of limitation and emphasise what can be done. Wearers of these products are presented as fun, social and out in public. There is no discourse of deficiency.

In contrast, the woman who wears an external breast prosthesis is subjected to reminders of the trauma of surgery with medicalised language such as “treatment” or “surgery”, or the narrative that she needs breasts to be beautiful and that she must maintain a socially acceptable appearance in order to be desirable. The basis is that the woman is deficient and needs the prosthesis in order to be whole and beautiful - a prosthesis is for “restoring beauty” and a means to “perfect your silhouette”. Furthermore, the notion of femininity is corporealised – it becomes synonymous with the breast and the perception of others is what validates it, rather than femininity being a personal intellectual or mental construct, and nothing to do with the body.

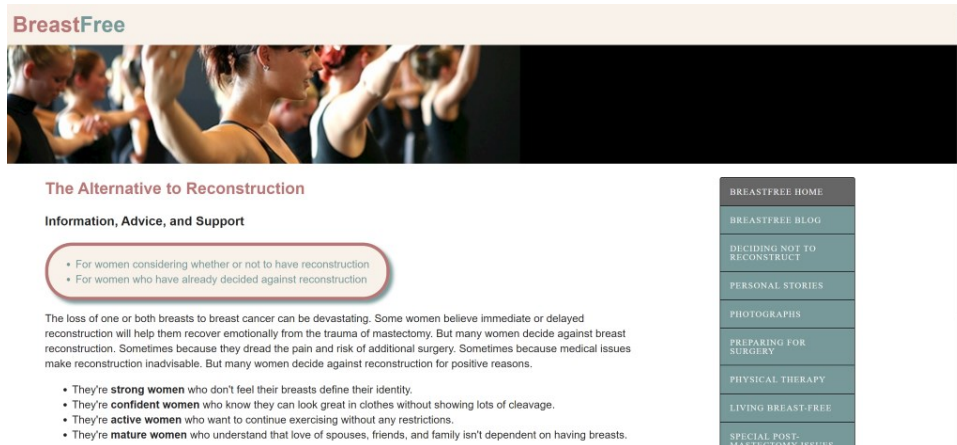
Gardner (2000), writing of the evolution of external breast prostheses in post-war America, argues that the incorporation of mastectomy products into lingerie boutiques was a strategic alignment with the beauty industry. The dominant culture’s focus on full breasts, and sexual allure equating femininity, provided the perfect platform to create a need in the consumer for this product as opposed to the newer

beauty messages that have emerged in recent years, focussing on body positivity and diversity.

Barnes (2008), also from America, in her overview of some of Audre Lorde's (American, Black, lesbian) writings on her breast cancer experiences says that impetus is put on the cosmetic instead of the power and opportunity for transformation. She exposes the rhetoric of the time and pervasive cultural attitudes which continue to inform attitudes in the present day.

Crompvoets (2012) argues that wholeness (as opposed to completeness) is psychological and in the discourse of commercial literature in Australia, is sold as tied to wearing a prosthesis. Like Lorde, she argues that the prosthesis evokes loss, while supposed to be restorative.

Websites or organisations eg <https://breastfree.org/> who espouse an alternative to reconstructive surgery are grassroots; they do not have the marketing and design budgets of cosmetic surgery practices. The non-contemporary quality of the web design will influence how their message is perceived and may present an alternative that is sub-consciously perceived as less appealing at the time she is making decisions about her body.



However, an alternative way to view it is to focus on the textual messaging which becomes easier with a no-hype visual aesthetic and text-focussed content. The breastfree website clearly communicates an alternative to commercial or surgical/medical discourses through its use of bulleted points and bold type:

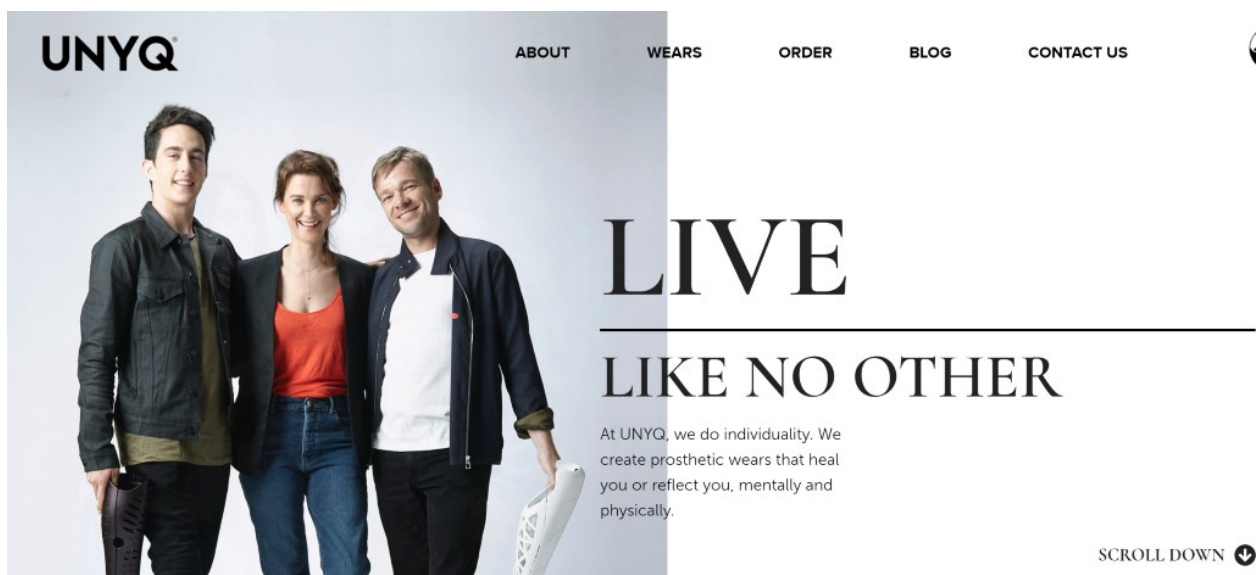
“But many women decide against reconstruction for positive reasons.

- *They're **strong women** who don't feel their breasts define their identity.*
- *They're **confident women** who know they can look great in clothes without showing lots of cleavage.*
- *They're **active women** who want to continue exercising without any restrictions.*
- *They're **mature women** who understand that love of spouses, friends, and family isn't dependent on having breasts.”*

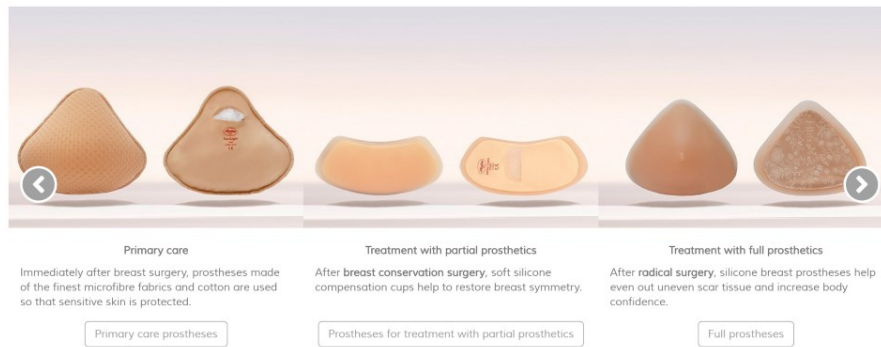
In contrast to <https://www.teamunlimbited.org/> - discourse on 3d printed limb prostheses, discourses around the prosthetic breast focus on the notion of wholeness or completeness.



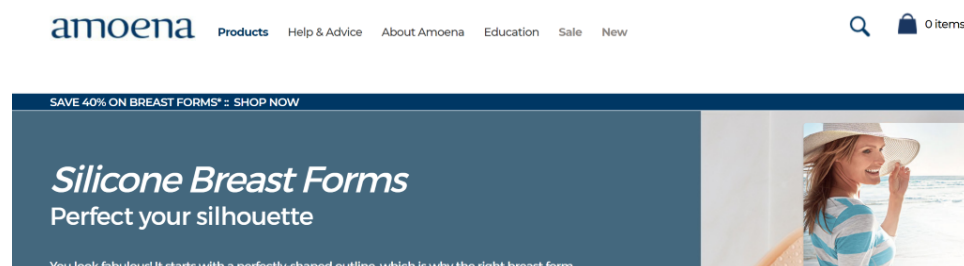
Team Unlimbited talk about empowerment and inspiration



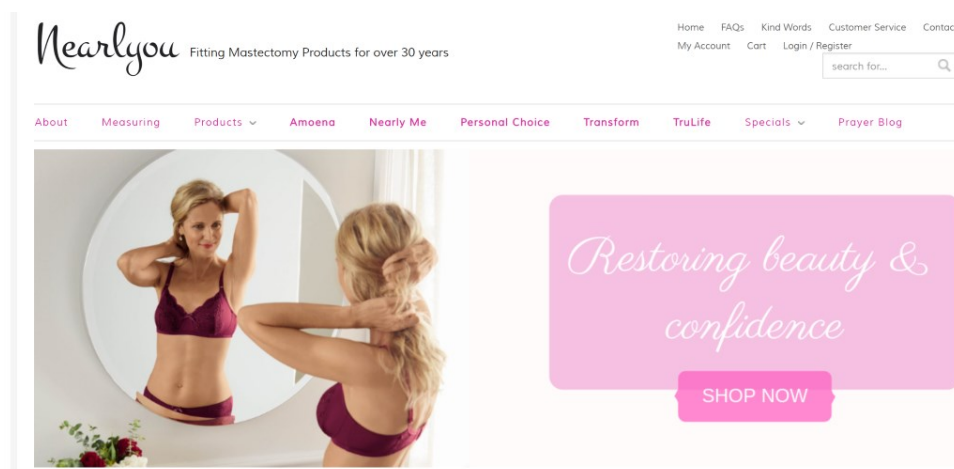
Unyq emphasise life, individuality, healing and reflecting you mentally and physically



## Treatment and medicalised language



## The need to be perfect – the message of being flawed and incomplete



## Implication that beauty has been taken away; plays on/creates insecurities



There is also a prevalence of narratives of completeness and wholeness being associated with wearing a prosthesis, and the tying of notions of feminine identity with having two breasts (real or otherwise). These place strong pressures on women to meet expectations, but it does not speak to the need to re-integrate the sense of self in adaptation to the changed body.

## **Conclusion**

Unlike prosthetic limbs, because the prosthetic breast does not have a function beyond being form-giving, it is not psychologically re-integrated into the body and maintains a sense of separateness. While some women seek to avoid confronting this by never being away from their prosthesis or by wearing a contact prosthesis for an increased sense of integration with the body, there is no changing the fact that mastectomy surgery and cancer have permanently changed the person behind the prosthesis.

## APPENDIX H

### FOUR THEMES: THE WEARER'S EXPERIENCE AND HOW TO IMPROVE IT

Early in my research, it became clear that comfort was of primary importance to wearers of EBP. However, trained in the arts, I could not accept that aesthetics should therefore be abandoned. I thus set out to understand all the aspects of wearing a prosthesis: public, private, practical, emotional, and understand how a number of considerations could be carefully balanced within the design of one product.

My position was not solitary: in her 1904 patent application for a solid breast pad, Laura Wolfe noted that women were concerned not just with comfort, but also with appearance and product quality<sup>28</sup>. In 1949, Max Bill famously made the case for beauty as having its own function, and a *gestalt* or harmonious whole, only being possible when there is form, function and beauty in one product. In 1992, Lamb and Kallal added expressiveness to this with their widely cited FEA Consumer needs model which considers functional, expressive and aesthetic qualities of apparel design, recognising the psychological dimension to product design and use.

As an outsider, my observation was that the EBP appeared utilitarian and lacked beauty. Wearers' observations were that it lacked the proper function or form to be comfortable and perform optimally. Understanding that all aspects of the user experience would affect appreciation of the product, I set out to understand how these could be brought into harmony, aiming to find a way to produce something that

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<sup>28</sup> <https://patents.google.com/patent/US814181A/en>

could be recognised as beautiful without sacrificing form or function. I had set out hoping to make the case for the psychological benefit of incorporating beauty or self-expression into a prosthesis and moved on to search for a means of addressing all the needs of the wearer, using co-design and design thinking to inform my practice.

Data from all interactions with research participants was reviewed and key words or concepts were extracted. These were clustered into areas of similarity, which in turn each fitted into one of four key areas relating to the wearer's experience and how it can be improved: physical, visual, psychological/relational and experiential. The themes and categories are detailed in table 1, below.

**Table 1: Four Themes for the EBP**

| <b>Physical</b>      | <b>Visual</b> | <b>Psychological/<br/>Relational</b>   | <b>Experiential</b> |
|----------------------|---------------|--|---------------------|
| Feel/Tactile quality | Ambivalence   | Social (others)                        | Affordances         |
| Performance          | Realism       | Self-image (self)                      | Affordability       |
| Structure/form       | Expressive    | Relationship to<br>prosthesis (object) | Accessibility       |

## **1. PHYSICAL**

Physical considerations were the primary focus for participants. The concerns can be grouped into three areas of structure/form, performance and feel/tactile quality.

### **Tactile Quality/Feel**

The most common comment about EBP is how heavy they are. While the weight is

designed to mimic the weight of a natural breast, because the prosthesis is detached or detachable, the wearer is aware of gravity acting on it, and its weight will tilt the prosthesis forward, exposing a flat chest wall, or it may even fall out. Conversely, if a woman is wearing a lightweight foam “softie”, the lack of weight means the prosthesis will move around, moving to the centre of her chest or travelling upwards and out of the bra so that it becomes exposed. Participants all specified a preference for the prosthesis to be smooth but the current material that is used to ensure the smoothness is also responsible for some of the objections that wearers have with its performance.

## **Performance**

The second most common complaint was how hot the prosthesis could get, causing the wearer to sweat, and not helped by those experiencing menopausal hot flushes (sometimes chemotherapy induced). The polyurethane film that encases the silicone gel is not absorbent, a quality some participants specified as desirable. Some were interested in the prospect of a cotton cover that would be more breathable. However, it seems reasonable to expect that heat and moisture regulation will continue to be an issue unless the structure is varied to allow genuine breathability or air circulation.

## **Structure/form**

An open structure was proposed to participants that could allow air to pass through, could be made adaptable (add/remove filling) and could perhaps have additional uses. This concept was well received by participants and was consequently developed into a commercial prototype and subsequent product.

Participants also noted that the form was not always right, that the standard teardrop shape and gently sloping profile with greater fullness at the bottom did not reflect the variety of shapes, sizes and age- or weight-related changes of natural breasts. While this issue can be resolved with a bespoke service of scanning and modelling a prosthesis, this is far from standard and for reasons of cost and efficiency, mass-manufactured prostheses remain the standard.

## **2. VISUAL**

The appearance of the prosthesis varies in importance depending on the wearer. For some, perhaps those who are highly attuned to aesthetics in general, a quality appearance, be that realistic or expressive, is desired. Others, meanwhile, are completely ambivalent to the appearance of the prosthesis.

### **Expressive**

Some wearers desire the objects in their lives to reflect and express their identity. For these women, the EBP should be no exception, and the EBP can become an extension of how she expresses herself. It was this attitude of “why not pink leopard print?” which inspired this research.

### **Realism**

For other women, the drive to minimise awareness of any bodily change is such that a realistic appearance is the most desirable. Depending on budget or access to this service, this may result in seeking the creation of an expensive bespoke prosthesis.

### **Ambivalence**

Yet other women are ambivalent to the appearance of the prosthesis. Wondering “what does it matter what it looks like if nobody sees it?”, these women’s primary interest is comfort. This may mean that realism in terms of colour, surface texture and weight are rejected in preference for a lightweight foam or colourful knitted breast form. Currently, these women may feel their needs for comfort are adequately addressed but the style of these items is lacking. Alternatively, they may be happy with the standard silicone gel prosthesis, not because of its appearance but because it represents the best overall wearing experience to date. If the physical and experiential elements of the EBP could be improved, this would be appreciated, and any resultant change to the appearance of the product would be incidental. In other words, the lack of realism is not an issue, any more than the presence of it is. However, it is difficult to ascertain whether this ambivalence is a defensive stance adopted due to the current lack of alternatives or whether, if presented with something that feels comfortable and looks beautiful, appearance suddenly becomes a greater priority.

### **3. PSYCHOLOGICAL/RELATIONAL**

The prosthesis stimulates a range of emotional and psychological processes and constructs. It is a medium/conduit for relational transactions to occur; it aids or hinders relationships between the wearer and others, the wearer and herself and the wearer and itself, the prosthesis. The prosthesis’ success is limited by the extent to which it allows the wearer to create satisfying relationships in each of these three areas. I argue that in each case, based on what participants have told me, these relationships can be improved.

## **Social (others)**

The primary reason for wearing a prosthesis is not for the wearer but for the onlooker (Giddens). Passing for “normal” and presenting as others expect avoids friction in social transactions. This is not even restricted to non-medical contexts (Lorde). However, full-busted women tell me that the silicone gel prosthesis lacks fullness at its top that is present in a breast and this results in a lack of cleavage. If the shape of the prosthesis were closer to the form a large natural breast takes when in a bra, then women would feel they were presenting themselves more as they would like to be seen.

## **Self-image (self)**

The prosthesis, whether under clothing, or worn adhered to the unclothed body, may shape how a woman perceives herself. Participants told me of feeling “unfeminine”, “maimed” and “partial” after mastectomy. Wearing a prosthesis helps some women feel more physically complete and feminine, even if this is only by way of others’ perceptions. That she is not publicly acknowledged as partial helps her to build her self-image as complete because she is treated as such, as opposed to being constantly reminded of her surgery – whether when dressing, catching sight of her reflection or noticing a stare or comment.

## **Relationship to prosthesis (object)**

The relationship a woman has with her prosthesis varies hugely between people. For some, the prosthesis is a “friend” that restores her shape and “helps save her life as it represents the cancer cells that have been removed”. Other participants told me they viewed the prosthesis as a “double edged sword”, or used language such as

“hate”.

How easy the prosthesis was to acquire, whether it is the first prosthesis or a replacement, how it looks to the wearer and the onlooker: all these influence the relationship a woman has to her prosthesis, not to mention the awareness of the reason for requiring a prosthesis in the first place. If any of these areas could be improved, then this would improve the relationship between the wearer and prosthesis. Instead of being something some women avoid, “just shove under the bed” or would fling across the room, by creating more positive associations with the prosthesis, perhaps it could become something more cherished and valued.

#### **4. EXPERIENTIAL**

While the support structure of regular hospital visits is missed when treatment stops, the continued medicalisation and re-entering of the "cancer system" to get a replacement prosthesis can't help but impact on pocket, self-esteem and ability to move on. Integrating the EBP into regular life in the same way as any other product, with design variation, appealing branding and packaging, increased ease of access and varied price points, would all help improve the user experience.

#### **Affordances**

While not a core theme, some participants did suggest that the prosthesis in its current form has limited affordances which could be expanded upon. For example, if a prosthesis were made adaptable, aspects such as fullness or weight could be varied according to need. Beyond these standard functional changes, some participants felt there was room for more creative thinking, suggesting the prosthesis



could become a radio, a monitoring device or a storage unit rather than simply providing structure under clothing. While not of primary concern, these comments demonstrate that wearers have ideas for how a prosthesis could be different and are open to sharing them, when asked. Not all ideas may be financially viable but by stepping away from a requirement for realism, new affordances become possible.

### **Affordability**

Of greater concern is the issue of cost. Affordability of post-surgery lingerie and the various lifestyle prostheses<sup>29</sup> that are required for different activities, as well as any desire to have early replacement or spare silicone gel prostheses, is an issue that needs addressing. While budget supermarkets are now producing post-surgery bras, and knitted breast forms are available for free, an affordable but stylish and pleasant retail experience is not currently available.

### **Accessibility**

Not only is there variability within health care trusts and individual doctors' practices as to information provided and the process observed regarding access to a replacement prosthesis, but assuming a woman understands she is entitled to a replacement prosthesis, it is not straightforward to get it. First, she must speak to her GP to gain a referral to the breast cancer care unit at her local hospital. Then she must be fitted for a bra or prosthesis by a representative of one of the prosthesis suppliers who are occasionally based at the hospital. If she is in luck, the

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<sup>29</sup> Prostheses made of different material(s), especially for wearing when exercising.

correct size prosthesis will be in stock at the hospital. If not, there will be a further wait while this is ordered, and a return visit will be required. If a woman ladders her tights in the morning, she can be wearing a replacement pair by lunchtime but if a woman's silicone gel prosthesis splits in the morning, she can be waiting for months before she can access a replacement.

If a woman is prepared to pay and knows the size that she needs, she can order a prosthesis online and receive one within a few days. However, given the lifespan of the product, that some women wear two prostheses and or different prostheses for different situations, this is a costly endeavour that will continue for the rest of her life, as long as she continues to wear a prosthesis.

Given that regular acquisitions are required, and that the number of women requiring a prosthesis is increasing<sup>30</sup>, it may be time to appraise the system and consider partnerships with retailers or new business models to increase the affordability and ease with which women can access the products they need, in a way that does not feel medicalised or like an afterthought.

## **Conclusion**

Based on participant feedback, only some of these four areas of physical, visual, psychological and experiential are currently being addressed, consistent with the literature. This indicates there are opportunities for product and service design development. That only some women feel they are being adequately catered for also

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<sup>30</sup> <https://www.credenceresearch.com/report/breast-prosthesis-market>

indicates a need to differentiate within the product offer and provide a greater range of choices to women after mastectomy.

## APPENDIX I

### DATA & ANALYSIS

#### 1. What's possible when we use empathy? A sample of the insights gained from data

If we adopt an empathic approach to design and make use of user narratives, we are provided with an emotional context for design and can consequently shape a better product and user experience. Sometimes, when we ask the right questions in the right way, we will discover profound insights which will influence what is designed and provide an excellent motive for redesign. To illustrate this in practice, here is some selective data derived from a narrative journeying/emotional mapping activity I ran with remote and workshop participants. Through analysis, it yields insights into wearer mindsets and how these mindsets interrelate to and shape other areas of life and culture. I draw out a number of themes present in the reported negative sentiments expressed and highlight the unspoken differences between how wearers feel and how they are perceived by others.

*“We all laugh about it but deep down I think we want to throw them across the room”*

*- JR*

With a mastectomy, body image, self-image and the physical body are all permanently altered. For those women who can accept this change and psychologically integrate it into their lives, the possibility of moving on – either with or without a prosthesis - is available, however challenging this may feel. For those

women who cannot accept this change, there is a psychological wound which leaves women feeling “battered”, “broken” and “bereft”. This state may eventually be remedied with either self-work, the support of others, wearing a prosthesis or further surgical interventions, but unless these are satisfactory, the altered self never fully heals. If these are satisfactory, self-acceptance and an attitude of “moving on” will come, but my interest lies with the women who feel deeply emotionally, physically and spiritually wounded. For the women who currently feel incomplete, unfeminine and unattractive or simply left behind and uncatered for, I would like to explore the ways in which re-imagining the prosthetic breast might lead to changes on individual, social, academic, medical and commercial levels.

Below are shown these two mindsets and how these might impact on the individual, society, academia, industry and medicine.

|                   | <b>“Battered, Broken &amp; Bereft”</b>             | <b>“Moving On”</b>  |
|-------------------|--|---|
| <b>Individual</b> | conforming   | liberated   |
|                   | passive  | (pro)active   |
|                   | medicalised  | independent   |
|                   | stuck  | moving on   |
|                   | limited  | feeling invincible  |
| <b>Social</b>     | hidden   | open-minded   |
|                   | taboo  | accepting   |
|                   | unknown  | aware   |
|                   | status quo   | new attitudes   |
| <b>Academic</b>   | woman as victim/patient                            | woman as empowered/independent                                    |
|                   | focus on medical experiences and surgical outcomes | exploring material/design alternatives and psychological outcomes |
|                   |  | deconstructing models of femininity and the body                  |
| <b>Commercial</b> | realism in products                                | self-expression, maybe customisation in products                  |
|                   |  | no product  |
| <b>Medical</b>    | multiple surgeries                                 | exploring alternatives to elective surgery                        |
|                   | corrective surgeries                               |   |
|                   | cosmetic solutions                                 |   |
|                   | mental health issues                               | self-acceptance   |

These are two quite different narratives. The lefthand column represents the current state of the product and the social climate which I believe gives rise to a negative reaction within women. Because EBP is hidden from view we don't necessarily know it is there, so we don't need to engage in thought or discussion about it. We are also now used to alternative limb/hand/foot prostheses being visible in public which leads to social acceptance and in turn, the assumption that if it is on show the person is OK and if it is hidden, it is either not there or it is there but not a problem/not to be spoken of, therefore, why would we ever consider there was an issue with an EBP?

Unless we show that which is hidden – understand the materiality and relational psychology of the EBP – how will we ever consider how it could be different, engage with the emotions at play or extend others' acceptance of difference to include breasts? It is for this reason that I focus on women's negative accounts of their cancer treatment and prosthesis wearing experience – be that physical or emotional - to identify where opportunities lie for development or improvement. The resultant benefits stand to be individual, social, academic, commercial and medical.

While there are certain recurring themes present in accounts and public forums, in this section I aim to share some of the lesser addressed areas, the hidden stories, if you will. In the sharing of this, I aim to help increase awareness among those of us who do not have direct experience of breast cancer, of which I am (so far) one. While it is not my place as an outsider to speak for women who have undergone mastectomy, I aim to synthesise what those who have, have shared with me, and I

hope in so doing, I can help to even slightly erode the taboos that exist around the emotional and psychological impact of mastectomy and EBP-use. When stories are not told, and experiences not shared, they will not be represented in culture or in commerce. While fully understandable, by remaining silent, the status quo is perpetuated.

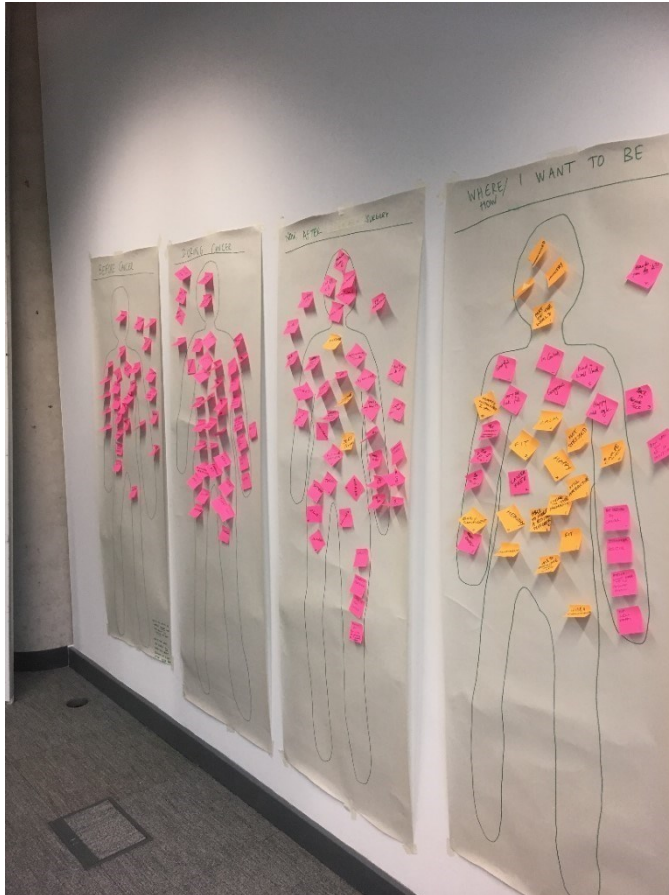
Where women have spoken out about discomfort, some manufacturers have sought to address wearers' issues with heaviness and heat. Unfortunately, these products are not reaching all women yet. But where women have not spoken out about dissatisfaction with the aesthetics, performance, psychological impact or user experience of their prostheses, these have not been adequately addressed.

In this section, I share the results of a simple activity that I believe profoundly demonstrates the need for designers, manufacturers and retailers to adopt an empathic approach and seek to understand the end user holistically, and not just in financial terms.

## **NEGATIVE EXPERIENCES**

When a woman has a mastectomy, there is a period of aftercare interactions to assess the progress of healing/scar tissue, and for psychological assessment, but after 6 months, there is no further engagement. It is primarily the physical or practical journey of the cancer-patient which is mapped, and not the emotional journey.

If we could create a map of a woman's emotional journey, how might this change the procedures, interventions and products that we make available to women?



Below are selected words provided by four participants which reflect how they would describe themselves at each of the three stages in their cancer journey, with a fourth column to indicate how they would like to feel. If we had a sense of the priorities for individual women then perhaps different opportunities would be offered.

|    | 1. Before  | 2. During | 3. Now    | 4. Ideal Future |
|----|------------|-----------|-----------|-----------------|
| 4A | Ordinary   | Freak     | Bereft    | Normal          |
| 2A | Sexy       | Struggled | Mutilated | Free            |
| 2D | Confident  | Dying     | Battered  | Body Confident  |
| 5D | Optimistic | Dark      | Fragile   | Happy           |



As you can see, there is a strong relationship between the before (1.) and ideal future (4.) columns; they are not identical, and so acknowledge that change has/will have occurred, but nevertheless, these words are positive words for the individual participants, describing their ideal state. The middle two stages of during and now indicate in some cases there is progress, in others deterioration, but in all cases these adjectives are negative, intense and emotive.

It is naïve to imagine that anything can help a woman skip straight from 1 to 4; I believe that in providing a realistic prosthesis, designers and manufacturers genuinely feel they are doing their best to address the ideals of 4 and help women to move as quickly to this place as possible. However, the words in column 4 are not in column 3, ie they are not being experienced in the present, despite all the women wearing a prosthesis, so the current prosthesis as a transformational object is clearly not working. Not to acknowledge the pain, fear, anger and multitude of emotions that are experienced during 2 and 3 means that women cannot arrive at 4 (in therapy the concept is “the only way out is through”). I therefore propose a way to acknowledge and recognise the feelings present in 2 and 3 as well as identify what 4 looks like and that this could be an aspiration, aim to respond to these either with an antidotal design, with a design which embodies or speaks to the qualities in 4 or which addresses other aspects of the wearer’s visual preferences or some aspect of personal meaning so that she can feel as she desires in column 4. It must be said that the way this is addressed may not be visual and may be fully addressed by providing greater comfort or breathability, for example. Each woman will be different, and if a more personalised approach can be taken, it could benefit the long term emotional and psychological outcomes for women.

In the Becoming exhibition, a limited number of words were selected to communicate the starkness of feeling during cancer treatment and how women felt now. This was deliberate and while not fully representative of the range of experiences and adjectives that participants provided, it was designed to communicate aspects that might be unknown and should not be ignored. That any of the words I selected are felt by anyone, is enough motivation for me to consider that any move towards creating a product that can help women to feel more positive, is a good thing.



Understanding the emotional journey of a product or service user can inform the development of an empathic design and in turn hopefully lead to a more positive experience for the user. No product or process can reverse the trauma of mastectomy, but do they need to add to it? Perhaps in a small way, elements of the negative could be mitigated with a different design approach. In Appendix D, I explore some phrases that could be true of a prosthesis if the design process were different, and these take into consideration the stated desires and ideas of participants.

Each group or remote participant was asked what description she would give to her prosthesis now and what description she would like to give. To gain additional insights, I asked participants to separate their answers based on how they would describe it and how others would describe it. Below is a complete example from participant 3B:

| NOW - OTHERS (Professionals) | NOW - OTHERS (Friends) | NOW - ME     |              |              |
|------------------------------|------------------------|--------------|--------------|--------------|
| Adequate                     | Unbelievable           | Rubbish      | FALSE        | Swimwear     |
| Acceptable                   | Expensive              | Triangle     | Ugly         | Grief        |
| Tape-able                    | Insulting              | Pink         | Simplistic   | Broken       |
| Fine                         | Barbaric               | Clear        | Insulting    | Commercial   |
| Good                         | Weird                  | Shape        | Embarrassing | Inanimate    |
| Grateful                     |                        | Mismatch     | Clumsy       | Slipping     |
| Modern                       |                        | Expensive    | Impractical  | Sleeping     |
| Positive                     |                        | Don't        | Wrong        | Bras         |
| Happy                        |                        | Resen[t]ment | Unnatural    | Fear         |
| Suitable                     |                        | Fragile      | Wonky        | Restrictions |
| Free                         |                        | Horrible     | Shapeless    | Unwanted     |
|                              |                        | Splitting    | Hidden       | Unloved      |
|                              |                        | Fake         | Necklines    | Other        |

| IDEAL - OTHERS (Professionals) | IDEAL - OTHERS (Friends) | IDEAL - ME |             |              |
|--------------------------------|--------------------------|------------|-------------|--------------|
|                                |                          | Fixed      | Confident   | Customisable |
|                                |                          | Normal     | Forget      | Practical    |
|                                |                          | Shaped     | Comfortable | Invisible    |
|                                |                          | Colour     | Easy        | Forgettable  |
|                                |                          | Matching   | Free        | Cleavage     |
|                                |                          | Real       | Replaceable | Pleased      |
|                                |                          | Realistic  | Many        |              |

3B's responses demonstrate the extent to which she perceives the current prosthesis to fall short in terms of physical and psychological affordances. The difference between the indignant responses of her friends, the unreservedly negative responses of her own and the positive responses of professionals provides an example of how there are many perspectives on the prosthesis and a lack of awareness of the internal experiences of the wearer. 3B's silence on what others would say about her ideal prosthesis indicates that she would not want the prosthesis to be observable or something that others pass comment on.

The purpose of this section is to share some of the hidden stories and expose how much these can be at odds with how women are perceived by others, in a bid to create better understanding, both in terms of the narratives that are perpetuated about breast cancer patients, and in the impact of 1:1 social interactions. While it is uncomfortable to read or to admit, all is not as it appears.

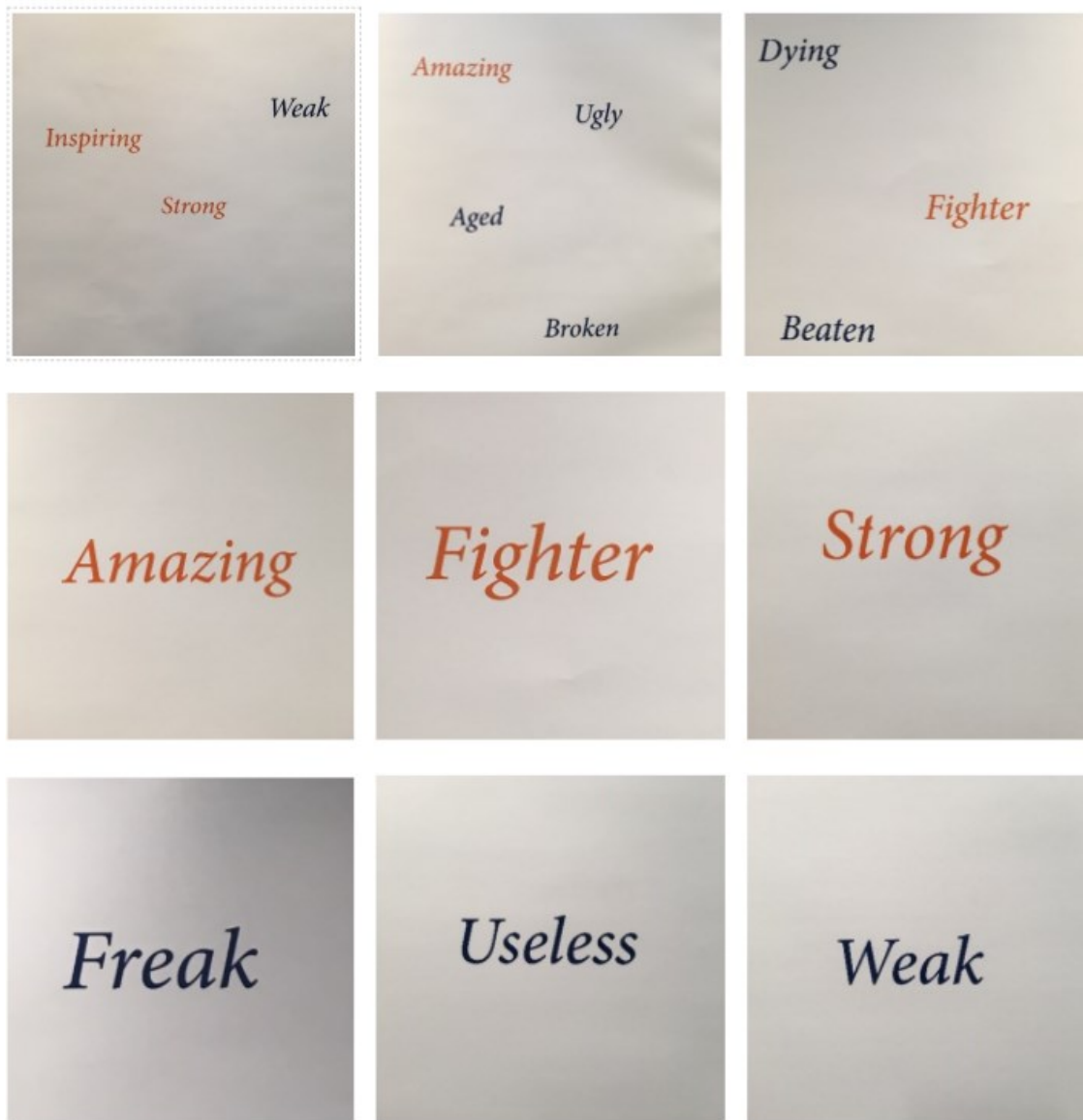
## ALL IS NOT AS IT APPEARS

There is a mismatch between the outward self that is presented to others or which others wish to perceive, and the inward self. Part of the desire for normality extends from social pressure to be seen to be well again and restored.

Below is an image of a text installation from the Becoming exhibition. Labels participants ascribed to themselves are depicted in blue, and labels others used of participants are depicted in orange.



Some of these words are antonyms of one another or hold contrary meanings. The words women choose to describe themselves are quite passive - things have been taken away from them or done to them. In contrast, the words others use of the women conjure the image of a proactive person who is conquering cancer through her sheer brilliance.



To be understood to be “normal” requires the body, both clothed and unclothed, to appear as much as possible, as it did prior to surgery. The internal self that can never be the same is at odds with this picture, so remains unspoken of, except maybe within the circles of a breast cancer support group. The desire remains unfulfilled. It cannot be answered but it could be sublimated or replaced with the desire for self-expression, afforded by a customised or personalised prosthesis, and therefore a “new normal” could be established.

The differences between how people think someone is and how that person feels are partly down to the taboos of (breast) cancer, and partly due to the desire or even need of 'the other person' for the cancer patient to be "back to normal", "well". The impact on relationships and families should not be underestimated and perhaps if it were easier to talk about the emotional impact of mastectomy and prosthesis-use, there could be better understanding and more honest or helpful conversations.

"People with breast cancer are supposed to be ourselves as we were before. But also better and stronger, and at the same time heart wrenchingly worse.

"We are supposed to keep our unhappiness to ourselves but donate our courage to everyone." *Anne Boyer, The Undying*

If there were more honesty and awareness of how women were really feeling during and after cancer treatment, then perhaps the contrasts between how women feel after a period of adjustment might be less in contrast with how others perceive them.

## **2 What's possible when we use co-design? A sample of the insights gained from data**

If we use co-design, not only can we learn things we never would have known otherwise, but we can generate ideas that we would never have arrived at alone. To illustrate this in practice, here is one small data set derived from one activity which, through analysis, yields ideas for several new products.

With this small data set, I explore how the varying requirements of six women might inform the development of wearer personas/mindsets which I would argue require different modes of address and different product offerings as priorities vary from person to person. At the very least, the common requirements within the group should inform the rethinking of the current prosthesis product.

### **1. THE DATA**

Six participants were provided with a pack of cards, each bearing a word or phrase which had emerged through research or practice. Participants were asked to bundle together all the desirable attributes, bind them and apply a gold star, bundle the undesirable attributes, bind them and apply a red star and then leave loose any cards which they felt ambivalent about. In a few instances, the cards returned did not amount to the full set; this could have been my error in not sending out a full set, or it could be that omitted cards represented those that the participant was ambivalent about and because they were loose, some simply were mislaid.

Where all six participants gave the same response, at a group level, this shows that there are some definite desirable qualities and definite undesirable qualities.



Key

Y = yes | N = no | A = ambivalent | O = omission

### Desirable Qualities

|    | Breathable | Smooth | Soft | Light weight | Fit in | Pretty | Feminine |
|----|------------|--------|------|--------------|--------|--------|----------|
| 1E | Y          | Y      | Y    | Y            | Y      | Y      | Y        |
| 2E | Y          | Y      | Y    | Y            | Y      | Y      | Y        |
| 3E | Y          | Y      | Y    | Y            | Y      | Y      | Y        |
| 4E | Y          | Y      | Y    | Y            | Y      | Y      | Y        |
| 5E | Y          | Y      | Y    | Y            | Y      | Y      | Y        |
| 6E | Y          | Y      | Y    | Y            | Y      | Y      | Y        |

### Undesirable Qualities

|    | Heavy | Stand out |
|----|-------|-----------|
| 1E | N     | N         |
| 2E | N     | N         |
| 3E | N     | N         |
| 4E | N     | N         |
| 5E | N     | N         |
| 6E | N     | N         |

Not all responses were unanimous, but plenty of qualities were commonly, if not consistently, agreed upon:

#### Predominantly Desirable Qualities

|    | Absorbent | Adaptable | Pastel | Normal | Lingerie | Nipple | Skin Tone | Lace |
|----|-----------|-----------|--------|--------|----------|--------|-----------|------|
| 1E | Y         | O         | Y      | N      | N        | N      | N         | Y    |
| 2E | Y         | Y         | N      | Y      | Y        | N      | Y         | N    |
| 3E | Y         | Y         | Y      | Y      | Y        | Y      | N         | Y    |
| 4E | Y         | A         | Y      | Y      | A        | Y      | Y         | N    |
| 5E | O         | Y         | Y      | Y      | Y        | Y      | Y         | Y    |
| 6E | Y         | Y         | Y      | Y      | Y        | Y      | Y         | Y    |

#### Predominantly Undesirable Qualities

|    | Textured | Firm | Tattoo | Robotic | Futuristic | Text | Solid* | Bright | Funky |
|----|----------|------|--------|---------|------------|------|--------|--------|-------|
| 1E | N        | N    | N      | N       | N          | N    | O      | N      | N     |
| 2E | N        | N    | A      | A       | A          | A    | N      | N      | Y     |
| 3E | N        | N    | N      | N       | N          | N    | O      | Y      | Y     |
| 4E | N        | N    | N      | N       | N          | N    | N      | N      | N     |
| 5E | N        | O    | N      | N       | N          | O    | O      | N      | N     |
| 6E | O        | N    | N      | O       | O          | N    | N      | N      | N     |

#### Ambiguous

This figure/table indicates where there are 50% responses for each of these descriptors as either negative or positive. Because of the remaining omitted or ambivalent responses, it is not possible to determine a clear picture of whether these are 50:50 or dominant towards one position or another. These areas would warrant repetition with a larger group to see how others respond to these areas and should

not be dismissed.

|    | Patterned | Lattice | Sexy | Fun | Humour |
|----|-----------|---------|------|-----|--------|
| 1E | Y         | Y       | N    | N   | N      |
| 2E | N         | N       | N    | Y   | A      |
| 3E | Y         | N       | Y    | Y   | Y      |
| 4E | N         | N       | A    | A   | A      |
| 5E | O         | O       | Y    | N   | Y      |
| 6E | N         | Y       | Y    | Y   | Y      |

### Mixed

Finally, there were some qualities for which there was a very mixed range of responses. The mixed response should not simply be interpreted as qualities without merit to be dismissed; this is a far too small number of respondents to make such a decision. What the variation does tell us is that - even within one individual's responses - there are some apparent contradictions within responses or there are multiple wishes, which suggests that women are looking for their prosthesis to either perform a variety of roles or for a range of prostheses to deliver these different roles.

|    | Personal Message | Colourful | Traditional | Surprising | Storage | Plain |
|----|------------------|-----------|-------------|------------|---------|-------|
| 1E | N                | N         | N           | N          | Y       | N     |
| 2E | Y                | Y         | A           | A          | A       | Y     |
| 3E | Y                | Y         | N           | Y          | N       | N     |
| 4E | N                | A         | Y           | A          | N       | A     |
| 5E | O                | O         | O           | O          | O       | O     |
| 6E | O                | N         | Y           | O          | O       | O     |

## Notes

The word “funky” is used here in its common UK slang form, as meaning “fashionable in an unusual and noticeable way” (Cambridge Dictionary online)

\* This set of responses cannot provide a reliable insight into the group’s attitude to whether “solid” is a desirable quality or not as half the responses were omissions. If these had been investigated and clarified, the resulting bias might be quite different. It would be inappropriate to infer ambivalence, or a negative response from the omissions, as tempting as it might be.

## 2. THE STORY OF THE DATA

To explore the story of the data, I focus on the responses that are either wholly or strongly based in one position or another.

Looking at the qualities that were listed on the cards, it was possible to categorise them into three groups: physical, visual and psychological. Each of these three categories had three further sub-categories. Physical included the feel, structure and performance of the prosthesis. Visual included the themes of style, realism and personalisation. Psychological included social aspects, self-image and experience.

| <b>Physical</b> | <b>Visual</b>   | <b>Psychological</b> |
|-----------------|-----------------|----------------------|
| Feel            | Style           | Social               |
| Performance     | Realism         | Self-image           |
| Structure       | Personalisation | Experience           |

### Physical

| <b>Feel</b>  | <b>Performance</b> | <b>Structure</b> |
|--------------|--------------------|------------------|
| Smooth       | Breathable         | Solid            |
| Textured     | Absorbent          | Lattice          |
| Heavy        | Storage            |                  |
| Light weight | Adaptable          |                  |
| Firm         |                    |                  |
| Soft         |                    |                  |

## Visual

| Style       | Realism  | Personalisation  |
|-------------|----------|------------------|
| Plain       | Nipple   | Photo            |
| Pastel      | Skintone | Text             |
| Bright      |          | Personal Message |
| Colourful   |          |                  |
| Lace        |          |                  |
| Lingerie    |          |                  |
| Pretty      |          |                  |
| Robotic     |          |                  |
| Futuristic  |          |                  |
| Traditional |          |                  |
| Patterned   |          |                  |
| Tattoo      |          |                  |

## Psychological

| Social    | Self-image | Experience |
|-----------|------------|------------|
| Fit in    | Feminine   | Fun        |
| Stand out | Sexy       | Humour     |
| Normal    | Funky      | Surprising |

At the time these cards were created, these categories were not consciously determined, but in retrospective analysis, I have grouped them to provide a way to understand what the data can tell us. The cards were initially designed as prompt cards to aid design workshops and the selection of words appearing on them was based on words from focus groups, interviews, literature review, public forums and my own practice. As such, the distribution of words appearing in any of these categories or themes is uneven and was never intended to be balanced. A more formal and equally weighted set of criteria could be created in future work and a repertory grid method might be appropriate for

determining preferences in a quantitative research or commercial context. I was aware of this method, but the purpose of these cards was as much to stimulate a response in the participants and then in me as the designer, as it was to gain hard insights into the preferences of groups.

## PHYSICAL

All participants in the group were looking for a prosthesis that was breathable, smooth, soft and lightweight. None of the participants wanted a prosthesis that was heavy. A prosthesis that was absorbent and adaptable was commonly desirable. Textured and firm were commonly undesirable qualities. How the prosthesis felt when being handled or worn was more frequently identified as important than how the prosthesis performed, but performance was also highly important.

## VISUAL

All participants in the group wanted their prosthesis to look pretty. Where participants had varied preferences for other qualities points to a degree of subjectivity on what may be considered 'pretty'. Associations with lingerie, lace and a pastel colour were commonly seen as desirable, as was the presence of a nipple and skin tone. These responses suggest a desire for two different prosthesis designs – one, a realistic skin-toned prosthesis with a nipple, the other, a pretty lingerie-inspired lace design in a pastel colour. There were no visual qualities which all participants agreed were undesirable, but commonly for this group undesirable qualities were reminiscent of tattoos, had a futuristic or robotic aesthetic, incorporated text or were brightly coloured. Responses on the visual style of the prosthesis were strongly weighted as clear likes or dislikes. This, plus the presence

of positive responses falling outside of the traditional realistic skin-toned paradigm, suggest that there is openness to broadening the visual styles available among prostheses.

## PSYCHOLOGICAL

All participants were looking for their prosthesis to help them fit in socially and feel feminine. No participants identified standing out as a desirable quality, and most selected “normal” as a desirable quality. Three of the group identified humour, sexy and fun as desirable qualities in a prosthesis, and two that a prosthesis be funky; however, this was mostly identified as an undesirable quality within the group. The responses suggest that the notion of self-image is important to the group. All wish to have a feminine self-image, but sexiness and funkiness were a *less important* part of self-image within the group. Socially, all of the group wanted to fit in, none wanted to stand out and generally, being perceived as normal was highly important. The type of psychological experience that the prosthesis could deliver – in this instance that of fun or humour – was of lesser importance than the social role of the prosthesis but roughly on a par with the less important aspects of self-image.

The prosthesis plays a large role in the psychological experience of the wearer. How the prosthesis is experienced by the wearer affects what they think about themselves, how they imagine they are perceived by others, whether they are entertained, delighted, amused or frustrated. Due attention should therefore be given to the potential psychological impact of the prosthesis, and just as there is precedent with ludic design (Gaver) and with plenty of designers introducing an



experience beyond the utilitarian or strictly functional, there is an opportunity to introduce whimsy, playfulness or unusual qualities that are designed to affect the emotional experience of the wearer and do not necessarily address physical or visual concerns.

### **3. HOW WE CAN USE THE DATA: PEOPLE, PRIORITIES, PRODUCTS & MINDSETS**

#### **PEOPLE and PRIORITIES**

Looking at an individual level, you will start to see different priorities - ie for some, there is the desire to look "normal/natural", for others, some prettiness, lace, lingerie, others are looking for humour, others for something bright and colourful, and so on. Aside from the physical aspects which all participants agreed would be desirable, when considering the visual and psychological, what different women have specified can tell us about new product development directions.

1E, 62, married, had a single mastectomy 12 years ago when she was 48

Visual: Non-realistic, pretty, pastel, pattern/lace

Psychological: No additional requirements

2E, 63, divorced, had a single mastectomy 12 years ago when she was 51

Visual: Colourful, personal message, no nipple

Psychological: Fun, funky

2E selected both colourful and skin tone. This suggests either that two prostheses would be desired or that the base of the prosthesis would be skin toned but with the addition of colourful text in a fun or funky font. Her responses are interesting because they combine some elements of realism (skin tone) but reject others

(nipple).

3E, 63, had a single mastectomy 15 years ago when she was 48

Visual: Bright, patterned, colourful, personalised elements

Psychological: Fun, humour, surprising, funky, sexy

3E appears enthusiastic about several qualities and open to something quite different from the standard product. However, like 2E, she still desires elements of realism: she does not want skin-tone but still wants a nipple. This suggests more about the form or appearance under clothing than it does about the surface aesthetics of the prosthesis itself. It's clear that 3E is open to something visually vibrant and full of the potential to entertain or provoke delight. This could create a very open brief to someone designing for her.

4E , 70, single, had a double mastectomy 13 years ago when she was 57

Visual: Realistic, traditional

Psychological: no additional requirements

For 4E, the standard type of prosthesis in terms of aesthetics is all that is required, simply updated for better comfort.

5E, 71, married, had a single mastectomy 6 years ago when she was 65

Visual: Realistic, pretty, lingerie, pastel, lace

Psychological: Sexy

For 5E, a skin toned base prosthesis with a nipple, covered in a lingerie style design (either flat or in relief) might be suitable.

6E, 85, widowed, had a single mastectomy 22 years ago when she was 63.

Visual: not bright, funky or patterned but open to most everything else, including a lattice type structure rather than it being solid

Psychological: Sexy, fun, humour

6E does not require the prosthesis to be solid. Providing the colour is not bright, the beauty and visual appeal of the prosthesis could come from its innovative structure. Additionally, the emphasis of this prosthesis need not necessarily be beauty but could equally be something more whimsical.

Who are we designing for?

The extent to which relationship status and age factor into requirements of a prosthesis will vary. For some, the function of a breast is purely maternal.

It is ill-advised to make assumptions based on age or marital status, but demographics and personal circumstances can be considered when looking at the responses of individuals. 6E, had her mastectomy over 20 years ago, whereas 5E, had hers just 6 years ago. The distance from the mastectomy and how long the woman has been wearing a prosthesis for, how often she replaces it, and any number of other factors will influence her requirements. Marital status may influence what is needed from a prosthesis in the context of a relationship, but of course

sexual activity is not limited to marriage, nor can it be presumed to be present within one. However, it is worth designers and manufacturers considering how life stages, lifestyles, relationships and time since mastectomy will all influence what a woman wants from a prosthesis and consequently, differentiation in product offer and messaging is sensible.

## PRODUCTS

Due to its commonality, the need to address comfort is assumed as standard. However, simply based on the divergent priorities of these participants, the potential psychological affordances and visual variations they express an interest in, here are six potential products that could be offered to women:

- pretty, lacy, pastel, feminine design over skin tone base, with nipple
- pretty, lacy, pastel, feminine – non-realistic form and colour
- Funky, colourful, bold, fun, sexy, personalised elements – coloured elements on skin-toned base/background - with or without a nipple
- Funky, colourful, bold, fun, sexy, personalised elements – full colour (no skin tone) - with or without a nipple
- Realistic prosthesis that is more comfortable and performs better
- Non-solid form with an innovative lattice structure – otherwise traditional in terms of colour palette

Inclusion of storage could be considered which increases the flexibility of the product to do more than just provide shape under clothing, but this is not a major concern.

Arguably, the inclusion of a nipple is not required for a design that is visually non-realistic. Even when opting for a skin-toned prosthesis, some women will question the need for a nipple, given what is currently provided does not accurately resemble one. However, some women find having the nipple is important, and certainly tattooed or prosthetic nipples are the thing that makes the biggest difference for women who opt for reconstruction. Designers could perhaps therefore consider how a removable nipple could become an additional element to these new prosthesis designs, part of what makes the prosthesis adaptable.

Aside from considering personal circumstances and visual preferences, being aware of the different mindsets or attitudes of a woman after mastectomy can also inform how products are developed and whether a prosthesis is indeed the right product for a person or whether there are other opportunities to develop apparel or accessories that would address the physical, visual or psychological needs and desires of the wearer. (see Mindsets After Mastectomy, in Chapter 4.2.2).

Using preference data provides insights into user lifestyles and priorities, providing designers with information that will guide them in designing better products and experiences. Preference data also provides insights into commonalities and divergences in requirements which can be useful in initiating and sequencing product development and can help create inform customer personas and mindsets so that product offerings and services can be differentiated and feel more personalised.

## APPENDIX J

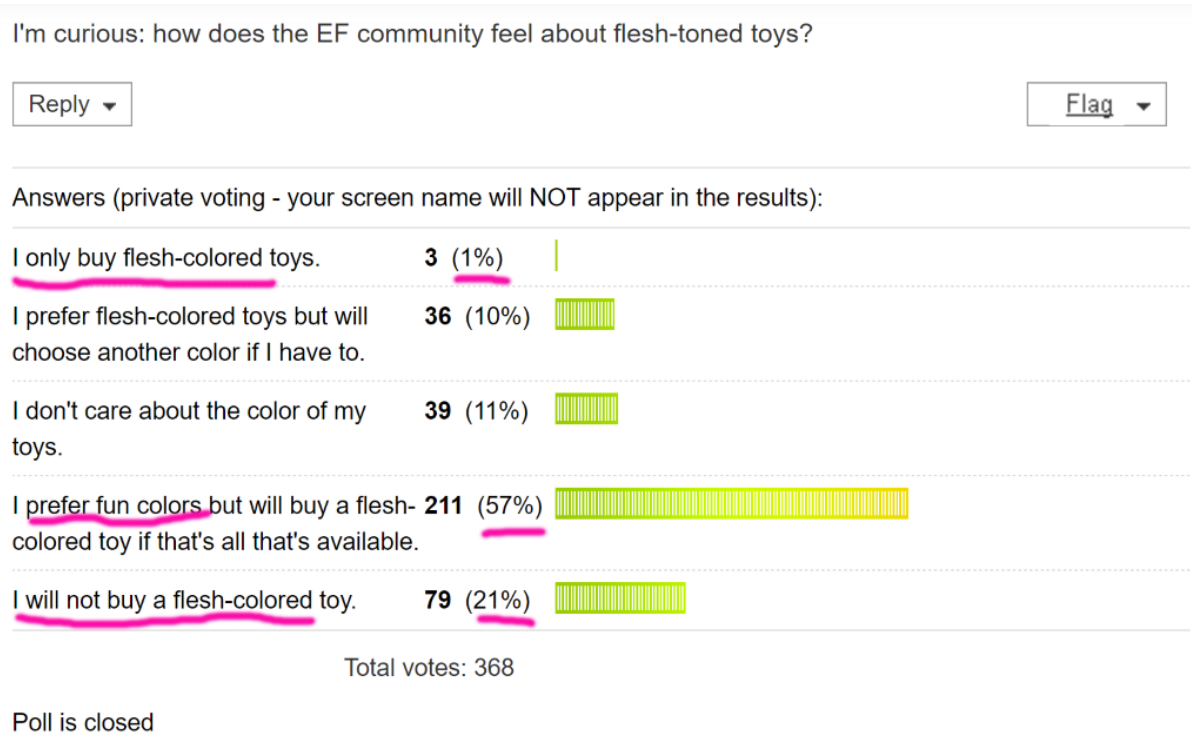
### **A look at realism in sex toys – an examination of data in the public domain on Australian website Eden Fantasies (2017).**

When considering alternative aesthetics for the external breast prosthesis, I looked at sex toys as a potential equivalent object, not because they share a function, but because they are both objects which are designed to resemble disembodied body parts, both are rarely used or seen in public and both are considered to be at least somewhat culturally taboo. Looking at attitudes to realism within the aesthetics of sex toys therefore, might provide insights into potential consumer preferences for realism within external breast prostheses.

I sourced two sets of aggregated data from an Australian sex toy website to assess attitudes towards realism in sex toys and then reviewed what the data told me.

The below quantitative data (*fig 1.*) provides a useful guide as to the relative frequency of attitudes within this online community. The sample size is large. Voting is anonymous, so it is reasonable to assume that people are voting their true feelings and are doing so in enough volume that it indicates a trend within this community.

The themes which people are voting on are set by the pollster which limits the insights available. Those who take part in the poll may be a self-selecting group who have strong feelings on the subject. Those members of the community who do not have strong preferences and so did not take part in the poll are not represented, so it is important to take a critical look at the data. However, if taking the data at face value then “fun” coloured toys are significantly more popular.

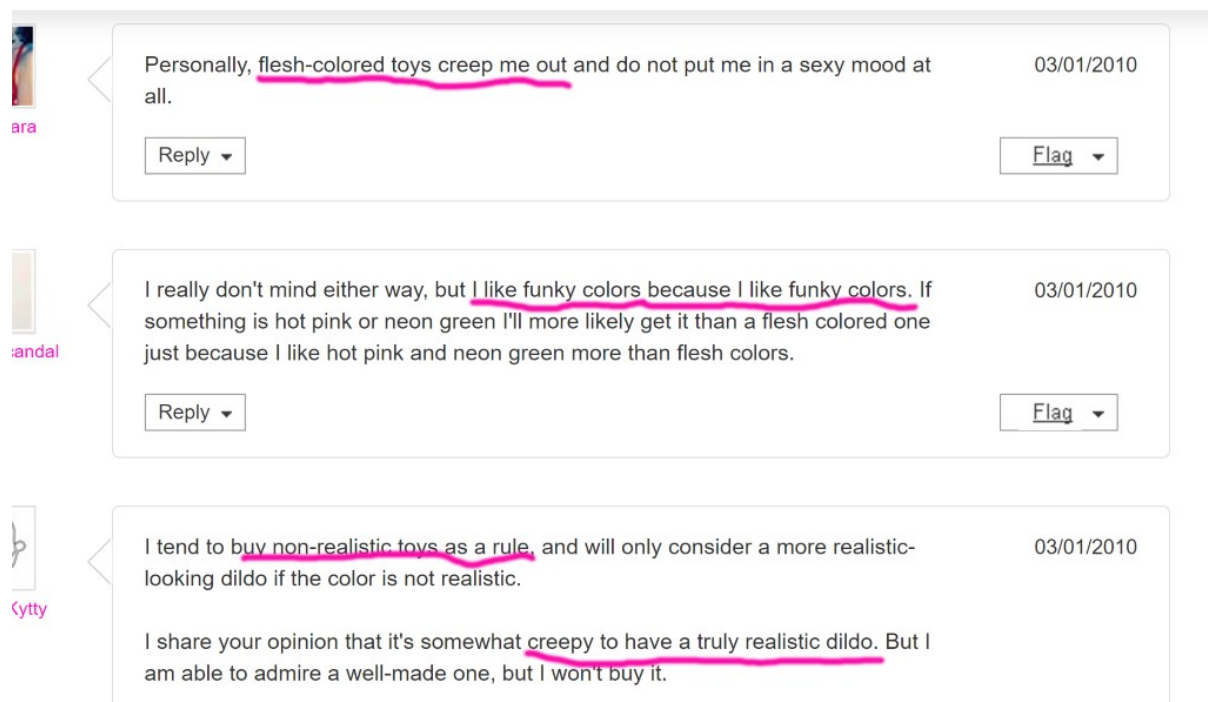


**Fig 1.** Edited screen capture of a poll from: <https://www.edenfantasys.com/sex-forum/sex-toys/dildos/how-do-you-feel-about/> (2017)

Qualitative data is also available in the same location about attitudes to realism within sex toys (*fig 2.*). Interestingly, unlike the poll, this is not anonymous (although I have cropped the image to obscure the online profiles of respondents so that I anonymise identities) yet people are candid about their opinions. The qualitative data is more immediately useful to a researcher because respondents are free to control the content and level of detail of their answers, so the data is richer, and can be analysed for themes about the nature of sex toy aesthetics. Some respondents talk about realistic aesthetics as being “creepy”. This response is consistent with Mori’s Uncanny Valley Theory (1970) in relation to human-like forms, if too realistic, evoking an uncanny feeling in the viewer. Other responses show that some people choose



items which reflect or express an element of their identity (“I like funky colours”).



**Fig 2:** Edited screen capture of conversation on: <https://www.edenfantasys.com/sex-forum/sex-toys/dildos/how-do-you-feel-about/> (2017)

## APPENDIX K

### A GUIDE TO RE-IMAGINING

The following prompts can be adapted to apply to whatever someone wishes to re-imagine. This could include a product, service, environment, or process:

- What new possibilities are created if the [item/subject] no longer needs to be [status quo]?
- What new structures could be created if the [item/subject] no longer needs to be [current form/format]?
- How might the [item/subject] design allow for customisation or personalisation?
- What designs might we create if the intention were to create something that made the user feel good?
- How might we make the [item/subject] beautiful and desirable?
- How might we make the [item/subject] fun to interact with or incorporate humour?
- How might we incorporate additional utility into the [subject]?
- What secondary uses could a [item/subject] have?
- What different designs might we create if the [item/subject] was going to be used in [new context]? Consider how the user is affected by their use of the [item/subject] in contexts where they are 1) with [strangers/clients/customers], 2) with [loved ones/neighbours/colleagues].
- What products could we design that would have wider application and appeal so that they are not a product solely for [current user group] with [specific circumstances/reason for use]?
- How might our designs help to encourage inclusivity and celebrate diversity?
- What might a co-design approach to [item/subject] design look like for us?