

APPENDICES TO THESIS

What matters in Making and Cloth(ing)-led Facilitation in healthcare?
Towards a practice framework for enhancing participation and
collaboration.
(Volume 2 of 2)

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APPENDIX A – WARDROBE PROBE DEVELOPMENT AND DESIGN

APPENDIX A.1. PILOT FEEDBACK – BREAST CANCER SERVICE USER

Recollective Threads - Home based activity pack (Wardrobe Probe)

Feedback - [REDACTED] (Previously undergone breast cancer treatment)

(If you can type your comments under each question below, that would be great. Please use the exercise number if you're referring to specific aspects of the activity. If it helps to add comments directly into the PDF of the activity pack, feel free).

GENERAL FEEDBACK - REFERRING TO THE PACK OVERALL

1. What are your thoughts on the Design format/layout?

I liked that there is space on the pages and not too much text. It also helps to keep the mind focused, so one's mind doesn't wear out reading a lot of text (that chemo brain/ brain fog 😊). The extra space came in handy for making notes.

The blue text colour and the lavender colour patches are calm colours to look at. It is great that you have used a vibrant orange for the "important" text and not a "danger" red. The different colour text and patches give pause and focus.

Perhaps Collection and Delivery info on page 9 could be moved to page 62. Because of my brain fog, I must focus very much, so my memory needs to concentrate on what is relevant right now.

But Useful Contacts should remain on page 9, so one has already read about them before eventually needing to use them.

Putting in break reminders after each activity is very important, so we don't get worn out. It is also great that you start each activity with estimated duration. It is a kind way to remind us not to exhaust ourselves or lose track of time. It also gives a good heads up on how much you expect us to work on each activity.

Outlining the Reflection boxes with orange gives a good frame to focus one's answer. I like the visual hanger tags for activities 1 and 4, they made me smile and anticipate a fun creative activity. Because I filled them in on the laptop, it was a bit difficult to write and switch lines in the two lower parts of the hanger because of the sloping sides. Perhaps make the vertical lines in the frames a bit higher if it does not interfere too much with the design. If you think most of the participants will fill in the hanger tags by hand, there is absolutely no need to change their design.

For my own reference and to save cognitive head space, I put a reference photo on most of the hanger tags for 1 and 4.

Good that you finish the activity pack with information on cancer support, if anyone should need to talk about emotions arising after the study is over.

2. Is the Introductory information (p.5-11) clear?

(Is there any important information missing?)

Clear and concise 😊

I suggest highlighting "at your own pace," on 2nd line page 6. It is an important gentle reminder that needs to stick in one's consciousness while doing the activities.

I suggest text about taking breaks during activities. Add to pg. 7 Suggestions on what one can do when emotions occur during activities. Emotions can occur during the activities, take a break, a cup of tea, play with your kid, have a chat with a loved one, watch a funny TV show, go for a walk to clear your head and heart and then return when you are ready. Make sure that you have someone to talk to if emotions occurring during the activities get difficult to handle. Perhaps a colour patch in a couple of the Activity pages reminding us to take a break if it gets to be a bit too much.

You mentioned that you would like me to photograph my process. If you also want the participants to do that during the collage and t-shirt activities, I don't think it is written anywhere in the information.

Is there a word missing in the last paragraph on pg. 11 *..for or to collect..??*

3. Are there key topics, that are relevant to people undergoing treatments for primary breast cancer, that are missing or that could be explored in this book?

I discovered that I developed a sort of very practical **treatment wardrobe**, of clothes that were chosen because of accessibility to veins, ports, bandages easy to get in and out of, easy to wash, no metal fasteners during radiation/scans. Also, that my choice of these clothes was based on saving energy when putting them on and off, and not on looks or fashion. They were very important in keeping some sort of personal individuality during hospital visits, when most of one's independence is removed so treatment can be as efficient as possible.

Perhaps include hair as a worn item on pg. 8. I was a bit unsure if **hair** is something you wear (it often gets to be for cancer patients). It definitely changes from pre, during to post treatment, and it is a very important factor of a person's looks during cancer. Wigs are mentioned on pg. 8, but I was unsure of including hair and its changes as one of the items.

4. Individual opportunities - Do you feel that there are benefits to using clothing-based methods to discuss experiences of diagnosis, treatment and/or recovery from primary breast cancer? If so, what might these be?

I was offered a lot of help from cancer support organisations in the form of support groups and sessions with psychotherapists and counsellors, but that is all talking and then when you are alone again you are left to thinking. It is positive if cancer sufferers have an activity where they can get all those thoughts and emotions out of their mind and body. These creative activities enable people through an active outlet that they also can use when they are alone. I will definitely use the collage techniques again to see how I feel before and after a cancer related change, and I will use the t-shirt tag activity when I get in a situation where I am swamped in difficult issues and don't know how to deal with them.

Using clothes-based issues removes the focus from the person onto an object which can make it easier to talk about difficult issues. Wardrobe mapping as an example is a safe way of talking about significantly difficult topics as well as situations where one was resourceful during and after treatment.

I have used how my dress needs changed as a therapeutic way of relating to cancer and what it has done to me, by posting about my clothes adaptations on social media. Writing the difficult issues into solving clothes-based problems made it easier for me to accept the changes, and it also gave me a forum where I could discuss these changes with people in similar situations or with people also very interested in clothes and fashion, it made me feel less different than the people not having cancer. And it felt much easier to use the clothes as a buffer than posting about the difficulties on their own. After my mastectomy I lost all beliefs in that I could ever be attractive to a partner again, and I still struggle with that, but the clothes help me to relate to that and deal with that in a safe way. I noticed this in the wardrobe mapping activity. How my focus had changed from before to after diagnosis. My focus is now, as my clothes are, more about feeling comfortable and relaxed with a partner than about being sexually attractive/active. I had not realized this before the activity and only carried a lot of sorrow that my sensuality wasn't as before my diagnosis. Now I can see that it is just different not gone.

5. Clinical/service opportunities - Are there gaps in service delivery or are there any specific clinical contexts that this type of activity may be appropriate/useful to patients and/or clinicians? If so, please describe.

The garment pattern collage would be a perfect activity before and after breast surgery. It can also be a good instigator for discussing difficult issues with family and kids. To do these collages together. If anyone had given me a piece of paper and a crayon when I was in hospital and in treatment it would have helped me immensely. I was too worn out to even come up with the thought that it could be good for me.

During my treatment I didn't paint/draw or collage anything because I knew it would be far too emotional for me if I did it on my own at home. I would have jumped at the offer if a cancer support centre had any of these activities.

The T-shirt tag activity (Activity 5) could also be a good way of helping people to figure out what kind of reconstruction they would like to have, their thoughts about the surgery and how it might feel after surgery.

Clothes based methods are extremely relevant when it comes to breast cancer, because mastectomy and reconstruction changes ones look immensely, and clothes are our cover and protection as well as our way of expressing who we are in public. Clothes are also a socially acceptable way of relating to the issues and changes that arise concerning one's body, sensuality, sexuality, and physical contact with a

partner. I found as a woman with no partner, that none of the health professionals acknowledge that I could have any sorrows about the loss/change of my look because I wasn't in a relationship, they basically shied away from helping me with my fears about the issue. Using clothes-based methods for discussing these issues could be a safe way for therapists and clinicians to address these issues. One thing I noticed with clinicians was that when I talked about how I healed and related to treatment through clothes, they felt ill at ease. As if it was vain to do so, as if when fighting for one's life, one shouldn't be concerned about looks. But it is when one is fighting for one's life that it is important to keep just the tiny bits that makes one's life look normal. Activities took longer than the estimated hours because of emotion-breaks. Taking it slow helped me to process. It helped me having all the clothes and collages on a clothes rack during the activities, seeing the clothes when I went in and out of the room sparked a lot of memories, I just had to go over and touch the fabric, put on the hat, or try the heels on again to get right back into the memories.

SPECIFIC FEEDBACK - REFERRING TO INDIVIDUAL ACTIVITIES

Activity 1 - Wardrobe Mapping

How is the clarity, structure, and relevance of this task?

It was very clear what I had to do. And the structure created a safe space to deal with difficult emotions. The task is very relevant because it visualises the clothing changes one has gone through and handling the clothes sparks physical memories. I even got a bit nauseated handling my chemo turban. It is also very relevant because one gets a sort of list of significant moments in one's cancer journey, also the happy moments.

Do you foresee any risks with discussing these topics in this way?

It took me more than an hour because I had to take breaks between choosing the pre-, during, and after clothes. I had to take breaks to calm my emotions especially choosing the pre- and during diagnosis clothes, because they represented loss and very painful memories. It hurt pulling out garments from my life pre cancer, sorrow of loss of my life pre cancer.

What are your thoughts on the concept of this activity - 'Selecting specific garments to reflect on significant moments/experiences.'

It really sparks my memories and is a great start, before the more creative activities. It makes sense to me because I often remember significant moments by what I wear. Handling the clothes awakens a tactile memory, of sound, smell, and taste.

Has this activity enabled you to reflect on your experiences of primary breast cancer in new ways? If so, how?

It felt very therapeutic. Sparked a lot of emotions and forgotten suppressed memories. I can see that I am able to adapt to any life changes and make them "work for me". That I can find and create positive/beautiful things/solutions from shitty circumstances.

Having to consciously relate to emotions and thoughts at specific times in my cancer journey. It was nice to have something to "project" my emotions onto. It was easier to relate to my emotions and painful situations through my clothes/what I had worn at that specific time, than if I had just had to talk about and remember the emotions. I noticed that it is easier for me to process my emotions if I have a creative outlet. Putting the outfits for pre cancer together was like recreating a life that is no longer mine, but tying it together with my life that is now. I realized that I do not really miss it all that much. The shoes hurt and the bra pinched the skin on my back, and my breath was limited by the bra 😊.

Do you have any recommended adjustments/improvements to the activity?

I attached photos to most of the hanger tags, it was easier for me to visually recognise the items, than to read the descriptions. Add a gentle reminder to take short breaks between the different stages?

Any further comments - anything that I may have missed, or that might be useful.

It was difficult for me to limit myself to 9 items. It made more sense to me, with the pre diagnosis clothes, to make ensembles than choosing separate items of clothing. I think I was trying to create a dream of something lost and missed. It was difficult describing the significance of the diagnosis clothes since most of my memory of that time has been wiped out because of the shock of being diagnosed with breast cancer. It took more than an hour, because it was difficult to limit myself to nine items, I also needed

breaks when the emotions got a bit too strong. I needed time to process emotions awakened by handling the clothes.

Activity 2 - Clothing Evolutions

How is the clarity, structure, and relevance of this task?

There was a lot to do in this activity and it took close to 2 hours, it is all relevant.

It was difficult for me to keep track of everything, and I made an index listing to help me:

Making a swatch card

Colour and Pattern

Style and Fit

Texture and Material.

Also, I switched the pages around and added headlines (see photo in returns pack), for it to be easier to navigate (the difficulty might be influenced by me having a pdf and photocopies, a book might make it easier to tell the different reflections pages apart.). However, it confused me that I had to list style as well as list fit before I reflected on style. My foggy brain could easier reflect on style right after I had listed it.

So, I arranged the pages, as follows, with explanatory headlines

Pg 25. Reflections on Colours and Patterns

Pg 26 - b) Thinking about style ~~and fit~~ (and adapted text to only be about style)

Pg 28 Reflections Style

Pg 27 Fit table - Write one word that best describes fit (repeat text from pg 26)

Pg 29 Reflections Fit

Pg 30

Pg 31 Reflections Texture and Materials

The headlines make it easier not having to read the entire text again if one loses focus during the exercise. If you want to keep the pages as they are, you could consider making a one-page style and fit listing followed by both reflections pages:

Style table		Fit table	
Example words	elegant, fun, comfy, sporty, sophisticated, formal,	Example words	baggy, tight, small, oversized, asymmetric, loose...
Item 1		Item 1	
Item 2		Item 2	
Item 3		Item 3	
Item 4		Item 4	

It also helped me to write the same short description I had used on the hanger tags in activity 1, under each item in the style/fit and texture/material tables.

What are your thoughts on the concept of this activity - 'Mapping changes in material aspects of wardrobe (colour, style/fit etc) to reflect on emotional and/or physical changes during cancer diagnosis, treatment and recovery).

It made it clear that good is not opposed to bad that happy is not opposed to sad. Instead it showed me differences and variety, and that both could exist at the same time which helped me to look with positive eyes at the emotions and memories from activity 1.

Do you foresee any risks with discussing these topics in this way?

This was a happy activity, and great that it followed the wardrobe mapping activity, as a sort of mood lifter.

Has this activity enabled you to reflect on your experiences of primary breast cancer in new ways? If so, how?

Describing all items with one word was an empowering experience and reading the words made me see that there was a lot of happy memories in my cancer experiences and memories of being resourceful in a difficult situation. Getting aware of my change in choice of clothes will help me not feeling as a fiasco every time I go to buy new clothes. Habit made me look for things that fit my old body. Now I have sort of a best choice shopping list for future buys. So I hope shopping for new clothes will be a more positive experience in the future. (at the end of doing all activities in the book, I have even discarded more of the clothes that no longer fit me, because I have become more aware of what fits me now, and why I like different sort of clothes now, it has become more apparent to me that there is no need to hang on to the last bits of my old wardrobe, because it no longer fits who I am or my reality.)

Do you have any recommended adjustments/improvements to the activity?

Because I had chosen, shoes, headwear, and jewellery in activity 1 it was difficult for me to get all my selected items to fit in the photo as suggested on Pg 25, so I did a sort of flat lay (photo in returns pack).

Any further comments - anything that I have missed, or that might be useful.

Activity 2a Great overview for seeing if there is a change in colour, texture, and pattern. I used it through all activity 2 and made myself a piece of paper with the photos and the swatch card for reference (photo in returns pack).

I cut colour swatches from magazines to swatch the straw hat and knitted compression garment. I wasn't sure whether it was colour, pattern, or texture that was the focus in making the swatch card. I think my swatch card is a bit messy, because it is a mix of magazine clippings, fabric swatches and drawn spots. It will be easier to see a change in colour if the swatches are cut from the same media.

Perhaps add gold and silver foil/paper to the swatch pack so participants can swatch jewellery

I used a paper lace napkin to swatch lace

I used a cut out template, scalpel, and cutting mat to cut my swatches, they still got a bit wonky 😊

Activity 3 - Then and Now

How is the clarity, structure, and relevance of this task?

Very easy to understand what to do, and the structure is clear (I was surprised though that there was not much difference between the two collages). The task is very relevant in understanding the layers of thoughts and emotions we carry around and how you can change them when you consciously relate to them.

What are your thoughts on the concept of this activity - 'Visualising expectations of breast surgery both before and following treatment.'

Liberating. That sad and happy can happen simultaneously, not being bad or good, just being there. Sad for the loss of a breast, happy that my reconstruction is "beautiful" sad that it will never feel like before, happy that the bit of my body that was trying to kill me now is gone, sad that my reconstruction is not symmetrical. I had hidden most of my thoughts about this part of my treatment away, just wanted to get on with my life. Great to experience that I can use my experiences and sorrow for creative purposes. It is something that I would have loved to do before my surgery, to deal with my fears.

Do you foresee any risks with discussing these topics in this way?

I noticed that both collages were sad and depicted pain, that really made me quite sorrowful, so I dug through my brain to see what positive images I could find and layered some of the happy images on top of the sad images, to care more for myself.

Having the blank garment pattern piece and writing my fears and anxieties onto it was difficult and hard, seeing them written out on paper made me feel sorry for myself. But it was so great to cover the words with the collage, and sort of erasing or covering them with my strengths. This was a difficult exercise, since it sparked some very painful memories, which fortunately got easier to deal with because of the creative activity. I anticipated it would be difficult, so I read the text at a quiet moment in the morning with a cup of coffee and spent the day thinking about it, and then did the collages in the afternoon/evening. It was good to spread it over the day, so I could keep up with my emotions.

Has this activity enabled you to reflect on your experiences of primary breast cancer in new ways? If so, how?

Certainly.

It has made me realize that creative activities are a great outlet for difficult emotions, and that it can get me thinking of positive ways to act instead of just feel sad.

It is great getting all these sad emotions of loss out of my body/mind/conscience and onto paper, so I don't have to carry them around. Putting the emotions on paper makes me look at the "artwork" as if it was made by someone else, and then it is not so difficult to handle.

Having a creative outlet for my emotions feels wonderful.

That I could change the feelings of pain, sorrow, and fear by adding positive words and images to the collage, after I had first added the sad images to the collage.

It was as if all the negative was cut and glued out of my mind onto the garment pattern.

Going through magazine clippings was a good way to make my diffuse emotions more concrete, because I had to make choices of what was important to depict and how to depict it, which made it easier for me to focus on the important issues.

I would love to make a t-shirt with the print of these to collages.

Do you have any recommended adjustments/improvements to the activity?

It took me longer because I first had to dig out the emotions (they were well hidden away), and I took breaks when the emotions got a bit difficult, also I did the Before-collage one day and the After-collage the next day. Doing both on the same day would have been a bit much?

Perhaps make it an option to make pattern pieces ½ size to minimize the use of time spent cutting and gluing. I chose a camisole as my garment, and even such a small garment had a lot of space to fill, which I enjoyed. But it would have taken me a week to collage a dress in full size.

As we talked about on the phone; the pros and cons of different ways of making Pg. 38 visually inspiring the participants creativity, with colours, pattern or photos on the page.

Also, that it might not be necessary, since they probably will be inspired opening the activity packet

Any further comments - anything that I have missed, or that might be useful.

Activity 4 – Adapt

How is the clarity, structure, and relevance of this task?

It is very clear and easy to use and structure with the hanger tags. The task is very relevant for discovering how resourceful we are adapting to situations we do not control. Lemonade out of lemons



What are your thoughts on the concept of this activity - 'Exploring how people have adapted to their circumstances (diagnosis, treatment and recovery) by reflecting on adaptations that they have made to their clothing.'

I love this, this is what has helped me to take charge of a situation in my life that I had absolutely no control over. Every single stitch of changing my pre diagnosis wardrobe, has helped me get closer to accepting my new situation and to dealing with all the obstacles I have met on the way. Being able to adapt my clothes has helped me to believe that I could adapt to my new situation and my changed body.

Do you foresee any risks with discussing these topics in this way?

It is sorrowful to be reminded of what I have lost, when listing all my discarded clothes.

Being reminded of the loss of a beautiful wardrobe that had taken me years to curate to perfection, and since it no longer fits neither my body nor my needs now, being reminded that I am just at the beginning of getting to know my new body and new needs, who by the way are constantly changing, and I am inexperienced in knowing how to accommodate my new needs dress wise. There is a lot of sorrow in realizing how much clothes/life I have lost and how little clothes/how new my situation is to me now

Has this activity enabled you to reflect on your experiences of primary breast cancer in new ways? If so, how?

Liberating to see what I had accomplished in terms of adapting clothes.

To experience that I am a resourceful person who can make good use of clothes that no longer works for who I am now, by adapting them to my current needs. Makes me think that this old, scarred, and battered woman is still worth something even with all the adaptations made to her recently 😊.

Hanging on to clothes that I can no longer wear only reminds me of what I have lost and discarding them frees space in my mind (and my closet 😊) to find new items that works for me now.

The clothes discarded are forgotten. The clothes saved in the basement are sad memories, the clothes adapted shows me that I can adapt to any situation, make it work for me and that I can make something positive out of a very undesirable situation

Made me notice my resourcefulness in finding solutions to my current challenges. Made me notice that I am getting experienced in adapting to circumstances.

Do you have any recommended adjustments/improvements to the activity?

It took me long to find the clothes and photograph them. It wasn't until after I saw the groupings and that there were a lot of sleeve changes and dress bodice removals, and that I could just have picked one of each 😊.

I needed more space for writing about the subjects on Pg. 47 than the subjects for Pgs. 50 and 51. It is difficult to foresee the future and I had a lot more to write about the past than about the future.

The same comments about the hanger tags for activity 4 as noted in the beginning of the feedback form.

Any further comments - anything that I have missed, or that might be useful.

I am still not sure I fully understood the activity on Pg. 49 Adapting your wardrobe to different contexts, but that might just be because English is my second language 😊

Activity 5 - Our Public and Private Selves

How is the clarity, structure, and relevance of this task?

The structure is very clear, and it is quite therapeutic going through the different steps. It is very relevant in discovering that pain can be changed to resourcefulness.

What are your thoughts on the concept of this activity - 'Exploring topics that are difficult to discuss - pre- and post-surgery - by working on the internal and external sides of a garment.'

I love it and it is very relevant, it visualises which issues are still not dealt with, and it certainly shows the lightness one feels after emotions are dealt with. Also, that you have to accept the different steps of the journey, that healing emotionally is a process that takes a very long time.

Do you foresee any risks with discussing these topics in this way?

It was hard to leave so many tags/issues still left on the inside of the t-shirt/me.

Now that the activity is over, they are still undealt with inside of me, now just very present in my consciousness where before the activity I did not think about them. It is a bit daunting having so many issues left and figuring out which to still repress 😊 and which to deal with when. Now a couple of days after finishing this activity new difficult issues comes to mind (but I now have a resource library to help me 😊).

Has this activity enabled you to reflect on your experiences of primary breast cancer in new ways? If so, how?

Gave me concrete knowledge of all the resources I have acquired in dealing with difficult issues. It was exceptionally wonderful to move so many tags to the outside of the shirt. So many difficult emotions now dealt with was very clearly visualized and made me full of hope for the rest of the internalized issues. It is wonderful writing and seeing these cards with the difficult issue on one side and the reasons for them being easier to talk about now, on the other side of the cards. It gives me a reference library on how to address issues that are difficult to talk about. The t-shirt went from being weighed down with loads of difficult stuff to being a truthful t-shirt of positive resources and support suggestions.

Writing 5d on the t-shirt also means that when you return the t-shirt to the participants, they can, while "wearing" the support suggestions on the t-shirt, use the resource reference library to deal with the cards that lists the issues that are still difficult. I like that thought 😊

Do you have any recommended adjustments/improvements to the activity?

I want to address the tags still on the inside of me/the t-shirt so I can move them to the outside. Perhaps, finish this exercise with a gentle reminder of this last exercise being an opportunity to talk these issues over with loved ones or professionals. So, this gets to be a positive experience. A gentle reminder to use some of the resources discovered in 5c and 5d to address the issues that are still difficult to talk about. Or to take contact to family, friends or cancer support services for any issues still not dealt with.

Any further comments - anything that I have missed, or that might be useful.

Great technique to dealing with difficult issues and discovering own resources, as well as where one is still in recovery. It visualizes that recovery is not linear. I needed a long break after writing tags in 5a. It hurt emotionally weighing my t-shirt/me down with all those difficult subjects (I noticed that I, in the garment pattern collage back, had put a photo that gave me much the same impression as seeing the inside of the t-shirt in activity 5a. Carrying a lot of weight. I needed to take breaks between 5abcd to process the thoughts and memories that arose. So, it took me more than an hour. It felt good to use a t-shirt of my own that I used to wear before my mastectomy. In 5b it meant a lot to me seeing the t-shirt scarred by pin holes from the many difficult issues I pinned to it. It reminded me of all the needle marks I have after treatment. I used a green sheet of paper for exercise 5d; colour of hope, growth, possibilities, and new beginnings.

On page 62

Perhaps finish off with some positive words in a colour patch, remind participants to now do something comforting and relaxing to close the activities, and to ease participants gently out of dealing with difficult emotions. A cup of tea, a short walk, play with the kids, watch a sitcom, meet a friend for coffee. That sort of suggestion.

APPENDIX A.2. PILOT FEEDBACK– BREAST CANCER CLINICIAN

Recollective Threads - Home based activity pack (Wardrobe Probe)

Feedback - Nicola Cunningham (Cancer Support Specialist)

(If you can type your comments under each question below that would be great. Please use the exercise number, if you're referring to specific aspects of the activity. If it helps to add comments directly into the PDF of the activity pack, feel free).

GENERAL FEEDBACK - REFERRING TO PACK OVERALL

1. What are your thoughts on Design format/layout?

I like it! It's well spaced with not too much detail on each page. I love the 'take a break' pages. The only question those raise for me, is, are people expected to do all the activities in one day? It feels like an enormous amount to do in one go. If they can do it in a more spaced way, maybe things like 'take 5' need to be changed slightly, so it's clear they can take hours away if they need to? I felt quite overwhelmed by the fact it's 66 pages long, until I got stuck in, and actually, once I looked at it in detail, I think the volume is about right- I can't see how you could reduce it without losing important info.

The 'tone' is great. It's clear, friendly and chatty.

Is there any way to make it clearer that a 'worn item' can be a complete outfit, rather than a single garment? It felt a bit of surprise when in activity 2, page 26, it asked for the whole outfit to be included (if relevant).

On each 'feedback' section, you ask people to consider various things, including 'pitch'. Pitch feels a bit jargon-y to me. Is there another way of saying that?

Is it worth suggesting that people have the contents of their activities packs in front of them as they read the instructions? It might help them picture what they need to do?

2. Is the Introductory information clear/relevant (p.5-11)?

Yes, absolutely. The only thing that worries me slightly is the use of 'scaffold' (pg.8). Is there a different word to use in its place? It feels slightly intellectual, in a way the rest of the info doesn't (which is a positive- it makes it more accessible)

3. Are there key topics that are relevant to people undergoing treatments for primary breast cancer, that are missing or that could be explored in this book?

Not that I can think of. It covers a lot.

4. Individual opportunities - Do you feel that there are benefits to using clothing based methods to discuss experiences of diagnosis, treatment and/or recovery from primary breast cancer? If so, what might these be?

Yes, I think so. I guess the fact that you can attach an emotion/set of emotions/emotional response to something that is personal you could allow people to open up more. They don't have to fully 'own' their feelings. Also, clothing is so visual. Simply saying 'I used to wear this, but now I wear this' could be very powerful in helping people to understand how the person has been affected.

5. Clinical/service opportunities - Are there gaps in service delivery or are there any specific clinical contexts that this type of activity may be appropriate/useful to patients and/or clinicians? If so, please describe.

Hmm. Interesting question. I think it could be appropriate in just about any context. Maybe in more challenging contexts - perhaps when reconstruction has gone wrong, maybe when discussing sexual intimacy or fertility?

SPECIFIC FEEDBACK - REFERRING TO INDIVIDUAL ACTIVITIES

Activity 1 - Wardrobe Mapping

How is the clarity, structure and relevance of this task?

It all made sense to me and was logically described.

Do you for see any risks with discussing these topics in this way?

I think the risk is the same through-out the activities; that someone will experience emotion that they aren't expecting, or thought they'd dealt with and have nowhere instantly to go with that. I am not necessarily going to be able to instantly answer an email. I recently did the Mental Health First Aid training, and we had to name a person who knew we were doing the course, with whom we could check in each day if we wanted/needed to. I wonder if that might work with this, too? I am happy to talk it over with you if that's helpful?

What are your thoughts on the concept of this activity - 'Selecting specific garments to reflect on significant moments/experiences.'

Works for me! The only potential issue might be that people have thrown them out already! Is there any scope for including photos of themselves wearing the garments, instead of the garment itself?

Do you have any recommended adjustments/improvements for the activity?

p.16, When you ask people to lay out the items, could you include 'or on the back of your door', as per the suggestions in how to take a good photo?

Any further comments - anything that I may have missed, or that might be useful.

No, it's great 😊

Activity 2 - Clothing Evolutions

How is the clarity, structure and relevance of this task?

Lovely and clear. Well described.

Do you for see any risks with discussing these topics in this way?

As previously.

What are your thoughts on the concept of this activity - 'Mapping changes in material aspects of wardrobe (colour, style/fit etc) to reflect on emotional, physical, social changes during cancer diagnosis, treatment and recovery)?'

I think it isn't something many people will have thought about, and I wonder if it will throw up things they weren't expecting. I'm expecting most 'fall out' after this activity.

Do you have any recommended adjustments/improvements for the activity?

Is there any way of including some drawn on pattern on page 24?

Any further comments - anything that I may have missed, or that might be useful.

Is there any benefit in suggesting people do something for their mental health self-care after this exercise? Maybe say that it might bring up unexpected thoughts and feelings and that taking some time to do something that they find relaxing/calming/balancing might be useful? Remind them to use their named person (if you include that) and/or to get in touch if they need to?

Activity 3 - Then and Now

How is the clarity, structure and relevance of this task?

Great! I had to read it through twice to check I'd understood, but again, I can't see how you can simplify the info.

Do you for see any risks with discussing these topics in this way?

As previously. Depending on the perceived outcome of the reconstruction, this might also be tricky for people. However, I think those who aren't happy with the outcome will already know that, so I don't think they'll be as surprised by finding that!

What are your thoughts on the concept of this activity - 'Visualising expectations of breast reconstruction surgery both before and following treatment.'

I can see that this could be a really useful tool for people who are considering revision of a 'poor' outcome and/or who are looking for psychological support to help with coming to terms with the changes in body image.

Do you have any recommended adjustments/improvements for the activity?

Nope 😊

Any further comments - anything that I may have missed, or that might be useful.

Activity 4 - Adapt

How is the clarity, structure and relevance of this task?

Great. I like that after a very 'crafty' task, there is a more written task. It creates a bit of breathing space.

Do you for see any risks with discussing these topics in this way?

No, nothing new

What are your thoughts on the concept of this activity - 'Exploring how people have adapted to their circumstances (diagnosis, treatment and recovery) by reflecting on adaptations that they have made to their clothing.'

It's great. It'll be interesting to see how many people include bras/underwear/nightwear here, where they may not have done earlier in the project.

Do you have any recommended adjustments/improvements for the activity?

Is there enough writing space on page 49? Or are you intentionally keeping it limited?

Any further comments - anything that I may have missed, or that might be useful.

Activity 5 - Our Public and Private Selves

How is the clarity, structure and relevance of this task?

Also great!

Do you for see any risks with discussing these topics in this way?

No, nothing new

What are your thoughts on the concept of this activity – 'Exploring topics that are difficult to discuss - pre and post-surgery - by working on the internal and external sides of a garment.'

I love this idea. It's so visual; I think it could be quite striking, but I'd hope in a positive way.

Do you have any recommended adjustments/improvements for the activity?

This is the activity that I needed to think about most to understand the instructions, and is really what prompted me to suggest you get people to have their packs to hand as they read the instructions. If you don't want to suggest that, is there any way you could include some pictures of what you're asking of them?

Any further comments - anything that I may have missed, or that might be useful.

No, nothing else.

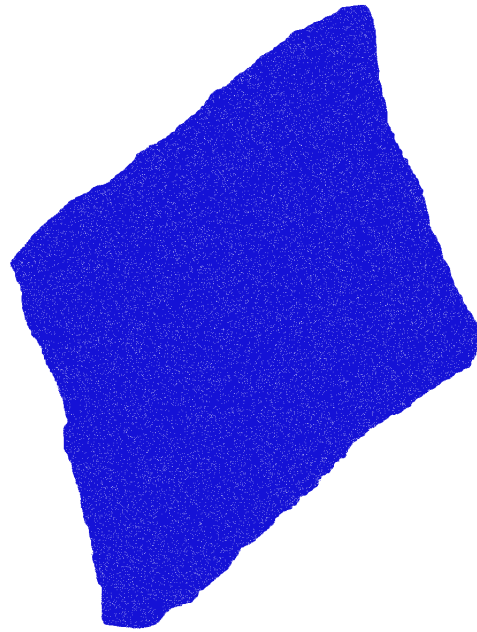
APPENDIX A.3. WARDROBE PROBE ACTIVITY BOOK AND
MATERIALS

Recollective Threads

2021

Content


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8-9	Useful Information
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32-33	Feedback form 2
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62-63	Returns Guidance
64	Useful Organisations



Hello and thank you for being part of
Recollective Threads.

My name's Rhian, I'm the research lead and your key
contact throughout the project.

Over the coming weeks, you'll be exploring the stories
attached to the things that you wear; thinking about
how your clothing may have changed since undergoing
breast reconstruction surgery. By building an
understanding of patient experience through these
activities, you will help to develop a set of creative
approaches to designing breast cancer services.



Our clothing can communicate
aspects of our identity, our
emotions or even key memories
or moments in our daily lives,
but how can our clothing help
us to talk about diagnosis,
treatment and recovery from
primary breast cancer?

Beginning...

This book contains 5 individual activities for you to work on, **at your own pace**, over the next **three weeks**.

Each activity contains;

A guide (offering step by step instructions).

A feedback form (to be completed at the end of each activity to collect your thoughts).

A set of materials to accompany each activity, which can be found in the allocated bags (please refer to the activity name and number on each bag).

There's also a digital camera for you to use throughout, which is yours to keep as a thank you for taking part.

Using **photography, word association** and **collage** you'll be encouraged to think about your wardrobe in a variety of creative ways; considering any changes that may have occurred before, during and following your treatment for primary breast cancer.

Can changes within your wardrobe communicate changes that may have occurred for you, personally, during this period of your life?

6

Self Care

Whilst being creative can be a positive outlet, it can also bring up emotions that are unexpected. It is important to look after yourself throughout the project.

We recommend doing each activity at an appropriate time for you or on a day when you have nothing else planned. At the end of each activity, you may also want to consider doing something that makes you feel uplifted—meeting a friend, listening to music, going for a walk—something for yourself that you wouldn't necessarily make time for.

Pacing yourself during the activities is also key and we have made suggestions of when to take breaks along the way—but please take a breather when it feels best for you.

Support

Nicola Cunningham (cancer support specialist) will be available via email and telephone to offer confidential support throughout the project. I'll be here to answer any further questions that you may have, as well as offering any practical advice when completing the activities in this book.

Additionally, we recommend that you identify a friend or family member who can act as a 'buddy' or a point of contact during the project.

You may choose to simply let them know more about the activities and when you'll be working on them. You may want to touch base with them at the end of a day to chat about how you are getting on.

A 'buddy' can offer informal support from someone that you are close to, in addition to the support provided by the Recollective Threads team. (Please take a little time before starting the activity pack to identify who your 'buddy' may be.)

Thank you again for taking part in this study. I look forward to working with you over the coming weeks.
Rhian

7

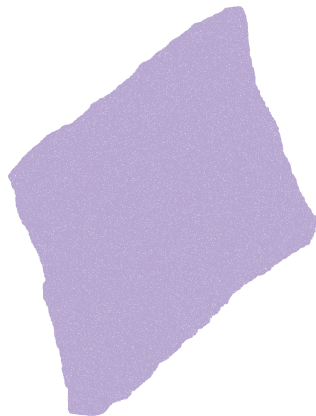
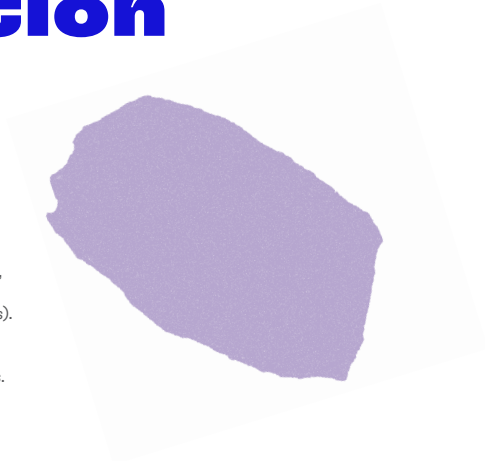
Useful Information

What counts as a 'worn item'?

The activities in this book will ask you to select individual or clusters of 'worn items' from your wardrobe to reflect on, creatively, in different ways. Worn items can be anything that you may have worn/wear on your body, and may include, (but are not limited to) clothing, underwear, outerwear (coats), accessories (handbags, wigs, scarves, jewellery) make-up, footwear, medical devices (prostheses, drains). Your selections are completely open to your interpretation. *Don't be alarmed if your selected items appear more than once across the five activities.

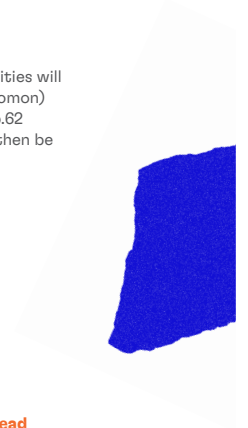
Activities and Documentation

The creative activities contained in this book are designed to be completed in a specific order (1 to 5), to develop your thinking and reflection. You'll also be making a lot of things along the way and it's important to keep them all together in one place. At the end of each activity, please return your creations to the Returns Package, marking any separate items with your initials.



Collection and Delivery

The content that you develop during these activities will be sent back to the study researcher (Rhian Solomon) for a 6 month period (the Returns guidance on p.62 provides further information about this). It will then be returned to you to keep.



Useful contacts

Rhian Solomon | Study Researcher & Project Lead

For any practical queries about undertaking the activities: rsolomon1@arts.ac.uk or 07800 907380.

Nicola Cunningham | Designated Cancer Support Specialist

For confidential emotional support during the project. nicolamcunningham@gmail.com

For further information about Rhian & Nicola visit www.recollective-threads.com/support

Professor Jane Harris and Professor Sandy Black | London College of Fashion Research Office

For any other queries or concerns about this project: University of the Arts London, 20 John Princes Street, London, W1G 0BJ or 0207 5147400.

Project Website

www.recollective-threads.com

Photography Guidance

Here's just a few tips to consider when photographing your selections of worn items...

Arrange your garment(s)

Try to **photograph your items on a lightly coloured, plain background**, eg. laid flat on the carpet or bed cover, or hung on the door or wall so that they're clearly displayed.

Photo format

Do you need to photograph your worn item in **landscape or portrait dimensions**? Hold the camera accordingly, making sure that it's **parallel to the item** when taking your snaps.

Aim to **have enough space around your worn item** for the image to be cropped, if necessary.

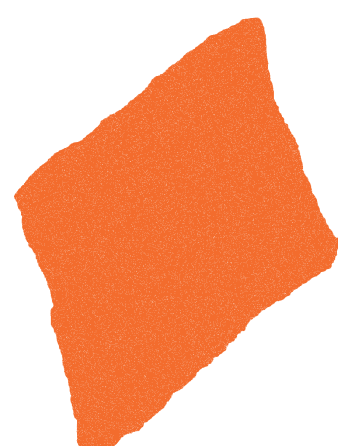
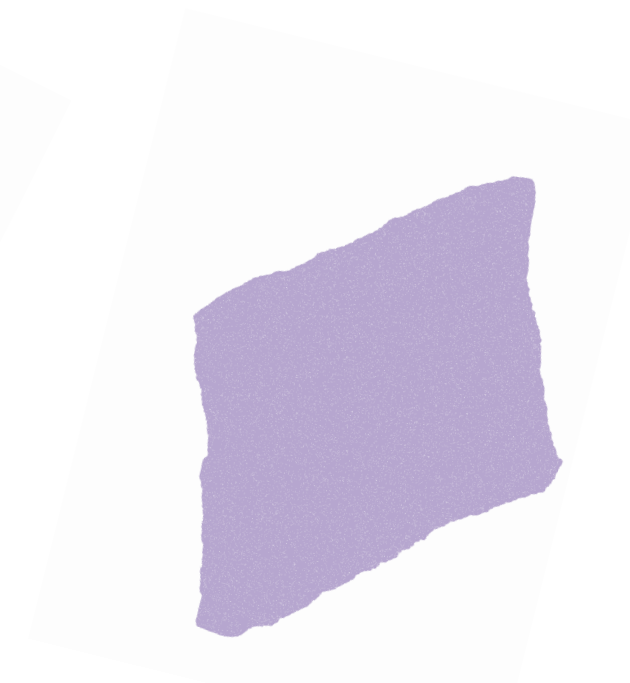
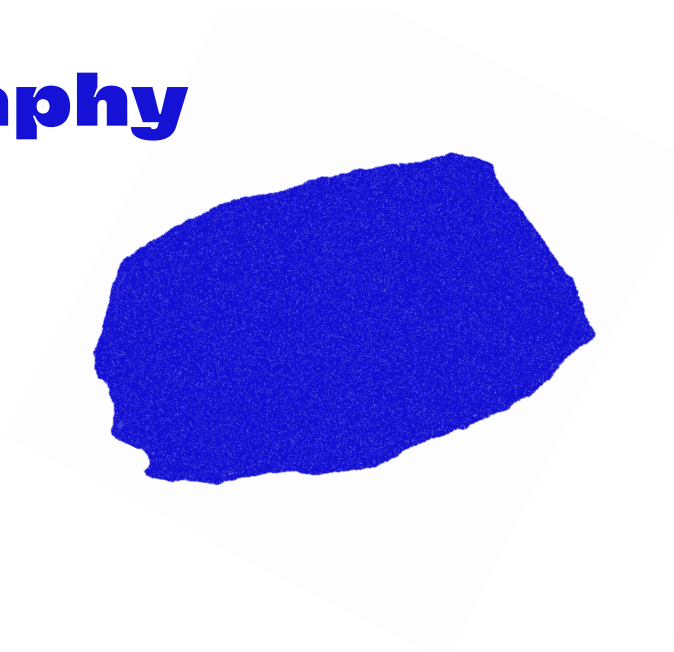
Take lots of photos. Your camera's memory card can fit multiple images, so don't feel limited to one or two.

Camera settings

To allow for automatic focus, **keep your camera on auto setting.**

Where possible, **aim to avoid the use of flash**, as this can block out colours and create reflections. Try switching the lights on in the room that you're photographing or take your pictures during daytime hours, in a well-lit space.

Keeping the time and date settings on will help to organise your images.

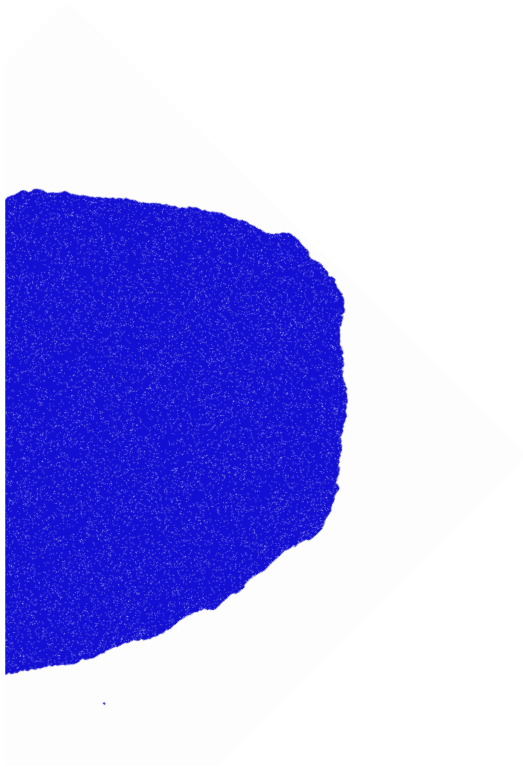
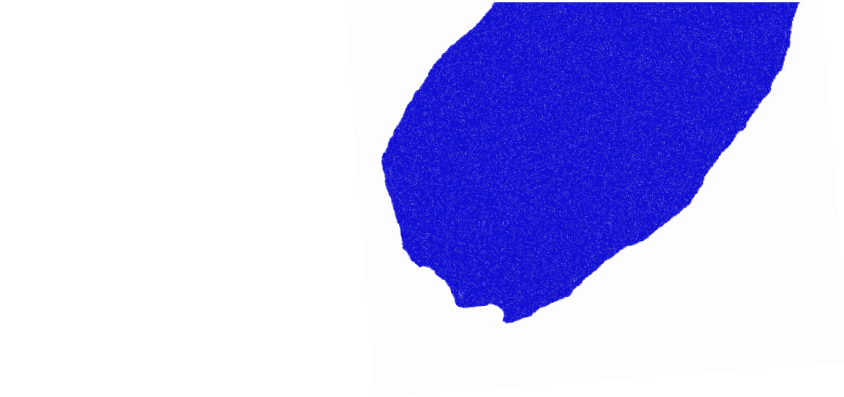


Sending your photos

After completing all of the five activities in this book... remove the memory card from your camera, and place it into the orange envelope provided in your camera box, seal it and write your initials on the front.

Place this envelope, along with your completed activity book with any accompanying material into the Returns Package provided, ready to send to the study researcher, Rhian Solomon.

A courier will be organised for collection.



Wardrobe Mapping

Wardrobe Mapping

1

This activity asks you to consider whether there have been significant moments during your diagnosis, treatment and recovery from primary breast cancer and whether worn items from your wardrobe may reflect these particular moments.

Duration **1.5 hrs**

(Please refer to materials package 1. Wardrobe Mapping)

Exercises

Stage 1

Please select **9** worn items from your wardrobe; **3** that you remember wearing pre-treatment, **3** during and **3** post, which reflect significant moments to you. For example, these may represent returning to work, meeting a new partner, your day of diagnosis. To consider your items in more detail, you may want to handle them and look at them more closely.

At this point, perhaps consider taking a break.

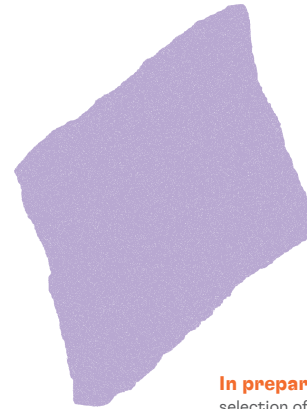
Stage 2

Including the hanger, arrange all of the items on the back of your door or bed (from past to present) and number them, in chronological order from 1–9. Then photograph each item individually, following this same order.

Stage 3

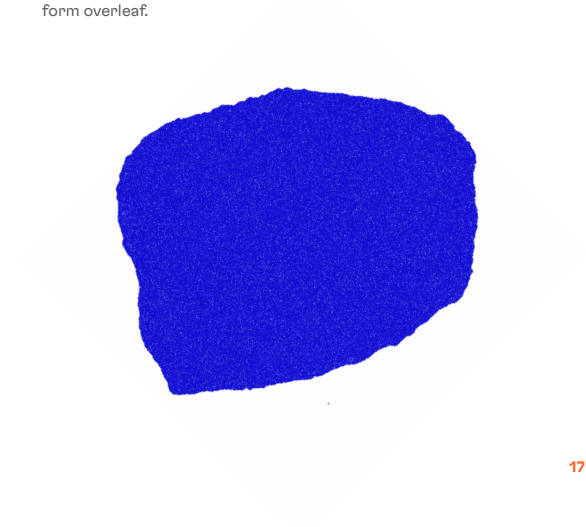
Now attach a tag, provided in your material pack, directly to each item's hanger and complete the information required—on the tag you will be asked to describe a little about each item and its significance to you.

16



In preparation for activity 2, place your entire selection of items back into your wardrobe, keeping them in the same order with their tags attached.

And take a few moments to complete the feedback form overleaf.



17

Feedback

This form will take approx. 5-10mins to complete.

Your feedback will help to improve the design of the activities featured in this book, so please be as detailed as you can with your responses.

1. How did you find doing these exercises?
(You may want to consider things like their duration, clarity or relevance to you)

2. What did you enjoy most about these exercises?

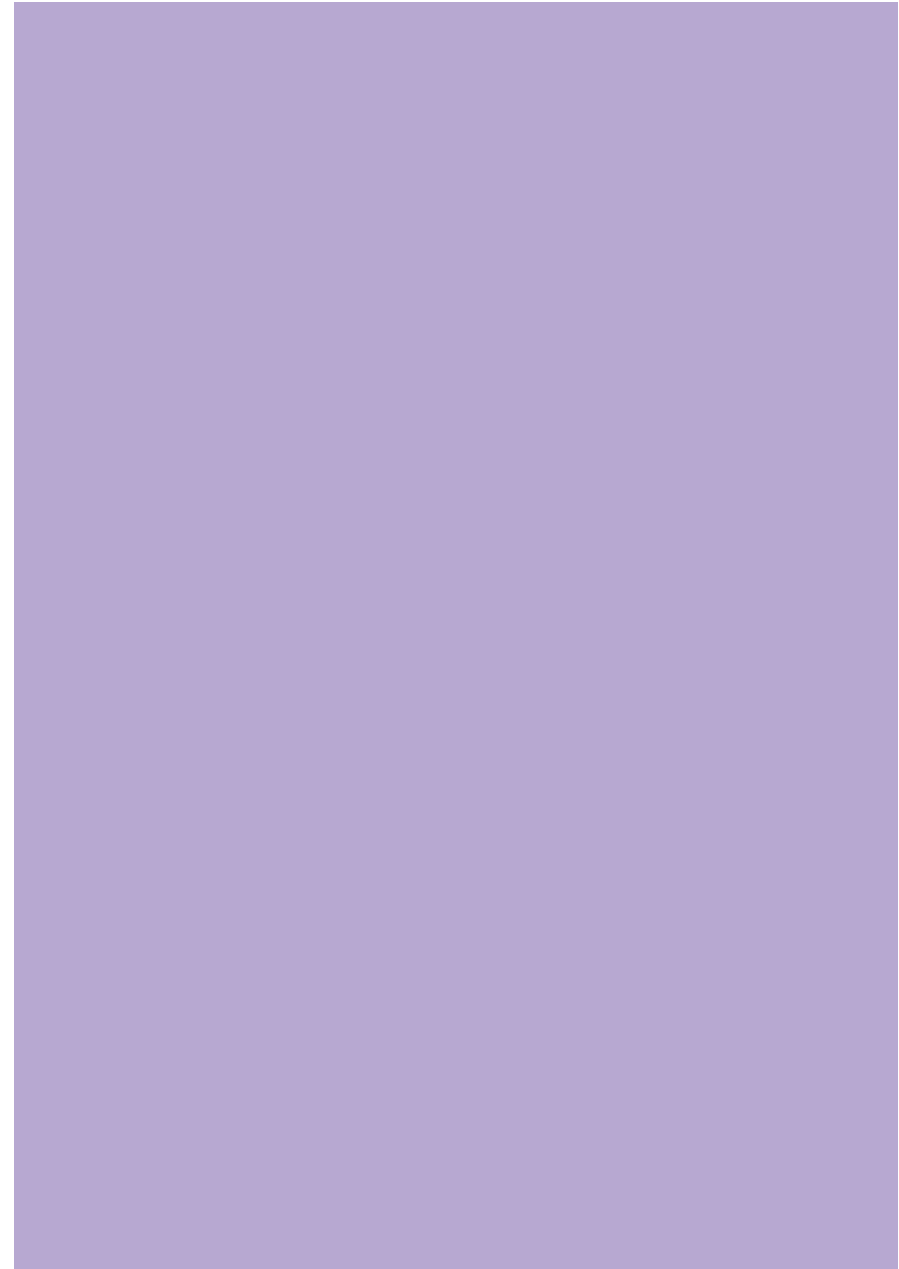
3. What did you enjoy least?

(Do you have any recommendations for how the exercises can be improved?)

4. What are your thoughts on the concept for these exercises?
i.e. Selecting specific garments from your wardrobe to reflect on significant life moments.

5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?

Time for a break.



Clothing Evolutions

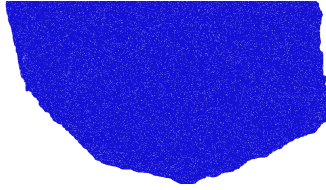
2

Has your wardrobe changed since diagnosis, treatment and recovery from primary breast cancer? If so, why might these changes have occurred? Using a variety of creative exercises during this activity you'll be asked to consider whether the colour, cut or cloth of your worn items have changed over time.

Duration 1.5 hrs

(Please refer to materials package 2. Clothing Evolutions)

Exercises



a) Thinking about colour and pattern...

Returning to the selection of worn items that you made during activity 1 (keeping them in the same order, 1–9) photograph them, as a collection from the side, as they hang together. Ensure that a section of each item is visible to the camera, see the example below. (You may need to photograph accessories and jewellery separately).

Using the paint colour chart provided in your materials pack, select and cut out swatches of colour that correspond with the colours of your worn items. (You may find that some garments feature multiple colours. Add a combination of swatches if needed. There are also metallic papers included to represent colours of jewellery). Glue these swatches into the blank grid below in consecutive order, from left to right. And draw on any additional surface pattern using biro if necessary. **Here's an example...**



Add your colour swatches here...



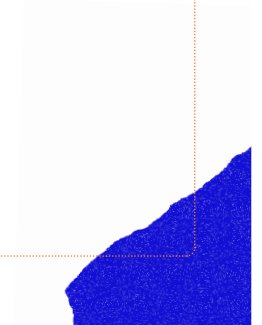
Reflections on colour and pattern

When looking at your worn items collectively, and referring to your colour swatches on the opposite page, do you feel that the colour and/or pattern of your worn items has changed over time?

If **not**, please move on to activity b.

If **so**, **how** have the colours/patterns of your worn items changed?

Why might they have changed?



b) Thinking about style and fit...

Returning to the same selection of worn items that you made during activity 1, keeping them in the same order, complete the blank table below and on the next page. For each garment write one word that best describes its style and one word that best describes its fit. Be sure to include all non-garment items, if relevant, such as jewellery, accessories, footwear. Don't worry if there is some repetition in the words that you use. **To consider your items in more detail, you may want to handle them and look at them more closely.**

Style table

Example words	elegant, fun, comfy, sporty, sophisticated, formal, muted, chic, smart, oversized...
Item 1	
Item 2	
Item 3	
Item 4	
Item 5	
Item 6	
Item 7	
Item 8	
Item 9	

Reflections on Style

When looking at your worn items collectively and referring to your completed table on the opposite page, do you feel that the style of your clothing has changed across time?

If not, please refer to activity c).

If so, how has the style of your worn items changed?

Why has it changed?



Fit table

Example words	baggy, tight, small, oversized, asymmetric, loose...
Item 1	
Item 2	
Item 3	
Item 4	
Item 5	
Item 6	
Item 7	
Item 8	
Item 9	

Reflections on Fit

When looking at your worn items collectively and referring to your completed table on the opposite page, do you feel that the fit of your clothing has changed across time?

If not, please refer to activity c).

If so, how has the fit of your worn items changed?

Why might it have changed?

c) Thinking about texture and material

Again, returning to the same selection of worn items, complete the blank table below, writing 1 key word which best describes the texture or material that each item is made from.

It may help to handle each item individually, to remind you of these qualities.

Texture/Material table

Example words	wooly, stretchy, worn, thick, tight, soft, scratchy, synthetic, bobbly
Item 1	
Item 2	
Item 3	
Item 4	
Item 5	
Item 6	
Item 7	
Item 8	
Item 9	

Reflections on Texture and Material

When looking at your worn items collectively and referring to your completed table on the opposite page, do you feel that the texture and/or materials of your worn items have changed across time?

If not, please complete the feedback form on the following page.

If so, how has the material and/or texture of your worn items changed?

Why might it have changed?

In preparation for your next creative activity...

Please remove all of the tags from your worn items and place them into the Returns Package, ready to send to the study researcher.

And take a few moments to complete the feedback form overleaf.

Feedback

This form will take approx. 5-10mins to complete.

1. How did you find doing these exercises?
(You may want to consider things like their duration, clarity or relevance to you)

2. What did you enjoy most about these exercises?

3. What did you enjoy least?

(Do you have any recommendations for how the exercises can be improved?)

4. What are your thoughts on the concept for these exercises?
i.e. Exploring material changes to your wardrobe to consider personal changes in your life.

5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?

Then & Now

Now take some time
for yourself.

*It might be that you feel upset
by some of the things that you
have thought about today.*

*Perhaps consider doing
something that makes you feel
good—meet a friend, listen to
music, go for a walk—something
that you wouldn't necessarily
make time to do.*

Then & Now



This activity will **explore** your expectations of breast reconstruction surgery, both before and following treatment. Has this changed across time?

Duration **2 hrs**

(Please refer to materials package 3. Then & Now)

Exercises

It's important to pace yourself throughout this activity.

Choose an item of clothing from your wardrobe.

From this item, you will be creating a very simple, two part garment pattern to collage into. (Consider the items size in relation to the size of collage that you wish to create, larger collages will potentially take longer to make).

Place your item onto the pattern paper provided and draw around it's outer edge (repeating this step, on a separate piece of paper, so that you have two identical drafted pattern pieces). Cut your pattern pieces out, and mark them individually as **Front** and **Back**, ensuring this remains visible to help to identify the pieces.

It's now time to choose the materials that you want to collage with...

A selection is provided in your materials pack, as a starting point. However, we recommend taking a little time to source some of your own items, as these can hold more meaning to you. You may have old garments, photos, magazines, books or packaging that you are happy to cut into. You may also want to collect materials from a particular place such as your home or your favourite outdoor space. Edible materials also work well from the kitchen cupboards, including pastas, seeds and pulses. Your material selections may also be based on how things feel, as well as how they smell, taste, sound.

Enjoy spending a little time considering your selections.

Using your materials selections..

a) Collage onto your back pattern piece

Images and/or text to convey the expectation/s that you had of your breast reconstruction, **before undergoing surgery.**

At this point we recommend taking a short break.

b) Collage onto your front pattern piece

Images and/or text to convey the expectation/s that you now hold of this procedure, **having undergone reconstructive surgery.**

Words taken from magazines and books can be used to state your thoughts or feelings. Different textures, layers and colours may represent different emotions. You might also consider drawing images or symbols freehand or creating your own textures using rubbings to suggest the things that were/are important to you.

How you interpret this activity is completely up to you.

Reflections

When looking at your completed collages: Do you feel that your expectations of breast reconstruction have changed across time?

If not, please complete the feedback form overleaf.

If so, how have your expectations changed? Please write your thoughts below. (If it's useful to continue onto another piece of paper, please do so.)

To conclude...

Ensure that your initials are written onto both collages, then fold/roll them ready to place into the Returns Package.

Now take a few moments to complete the feedback form on the following page.

Feedback

This form will take approx. 5-10mins to complete.

1. How did you find doing these exercises?
(You may want to consider things like their duration, clarity or relevance to you)

2. What did you enjoy most about these exercises?

3. What did you enjoy least?

(Do you have any recommendations for how the exercises can be improved?)

4. What are your thoughts on the concept for these exercises?
i.e. Collaging the back and front panels of a garment pattern to consider your past and present expectations of breast reconstruction surgery.

5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?

Adapt

Time for a cuppa...
or perhaps a check in
with your 'buddy'?

Adapt

4

Have you adapted individual garments from your wardrobe or made changes to how you wear your clothes since diagnosis and treatment for primary breast cancer? This activity will explore clothing and wardrobe alterations with a view to thinking about any life changes or personal adjustments which may have occurred for you during this time.

Duration 1 hr

(Please refer to materials package 4. Adapt)

Exercises

For this activity, you will be creating new clusters of garments, that are different to those selected during previous activities. Please don't worry if there is some repetition of items, however.

a) Adapting individual garments

Since diagnosis and treatment for primary breast cancer, have you adapted (or had adaptations professionally made to) garments from your wardrobe? This might include changes made to the fit, style or function of the garment.

If not, please move on to exercise b.

If so, lay each of your adapted garments out flat on your bed or floor (including their hanger) and photograph, close up, the changes that you have made. (If you have adapted multiple garments in the same way, perhaps choose one example of each adaptation to photograph).

Now attach a tag, provided in your materials pack, directly to each garments hanger and complete the information required. (On the tag you will be asked to describe a little about the alterations that you have made/have had made professionally).

b) Adapting how you wear your garments

Since diagnosis and treatment for primary breast cancer, have you adapted **the way that you wear your clothes?** (This may include changes to wearing certain clothing combinations, or to your overall style. It may also involve things that you no longer wear).

If not, please move on to exercise c.

If so, please describe these adaptations and your reasons for making them in the box on the opposite page.

It may help to take items of clothing out of your wardrobe to consider during this exercise.

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Reflections

How has the way that you wear your clothing changed?

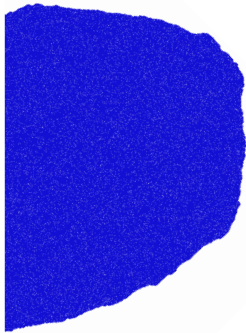
Why has the way that you wear your clothing changed?

c) Adapting to context

Since diagnosis and treatment for primary breast cancer, has the way that you wear clothing changed within any of the following settings eg. **Personal** (eg. the home, in hospital) **Recreational** (eg. Social events/celebrations, sports activities, travel) **Professional** (eg. returning to work, wearing a uniform, starting a new job, attending a job interview, formal activities).

If not, please move on to exercise d.

If so, please complete the task opposite by describing, in the relevant sections, how you have changed your selections and/or style of clothing in personal, recreational or professional contexts.



It may help to choose a cluster of items from your wardrobe from pre, during and post reconstruction to consider during this activity.

space for additional comments...

How have your selections and style of clothing changed in personal, recreational and professional settings?

Personal

Recreational

Professional

Since diagnosis and treatment for primary breast cancer, have you discarded any clothes?

Please use this space to write down any items that you may have disposed of and why?

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____



Thinking about the clothing that you have discarded can be upsetting... however, it may also be a reminder of moving forwards with your life.

d) Future Threads

Do you foresee making any adaptations to your wardrobe in the future?

Reflections

If not, please complete the feedback form overleaf.

If so, how might you adapt the way that you wear your clothing in the future and why?

In preparation for activity 5 please remove all of the tags from your garments and return them to the Returns Package. You can now also place your cluster of garments back into your wardrobe as you've finished working with them.

Please take a few moments to complete the feedback form overleaf.

Feedback

This form will take approx. 5-10mins to complete.

1. How did you find doing these exercises?
(You may want to consider things like their duration, clarity or relevance to you)

2. What did you enjoy most about these exercises?

3. What did you enjoy least?

(Do you have any recommendations for how the exercises can be improved?)

4. What are your thoughts on the concept for these exercises?
**i.e. Exploring adaptations that you've made to your clothing/
wardrobe to reflect on personal adjustments that you've made
in your life.**

5. Have these exercises helped you to reflect on your
experiences of primary breast cancer in new ways? If so, how?

Our Public & Private Selves

Now, take a breather.

Our Public & Private Selves



5

Talking with others about diagnosis, treatment and recovery from primary breast cancer can be difficult at times. This exercise will explore any topics that you may have found challenging to speak about and will ask you to suggest ideas for how these conversations can be better supported in the future.

Duration 1.5 hrs

(Please refer to materials package 5. Our Public & Private Selves)

Exercises

a) Were there things that you found difficult to discuss during your diagnosis, treatment and/or recovery from primary breast cancer?

If not, please move on to exercise b)

If so, please complete exercise a) below

Using the velcro tags provided in your materials pack, please write key words onto each, to signify the **topics** that you have found most difficult to discuss. For example, these might include diagnosis, physical intimacy, bodily changes. Now stick each of the tags individually, to the inside of the lilac garment in your materials pack, by removing the plastic backs from the velcro dot. Make sure that your writing is face up.

b) Having now completed your treatment for primary breast cancer, are there topics which you feel that, today, you are more able to discuss or share with others?

If not, please move on to exercise d)

If so, move the velcro tags that correspond with these select topics, from the inside of your garment to the outside and position them writing side down.

At this point we recommend taking a short break.

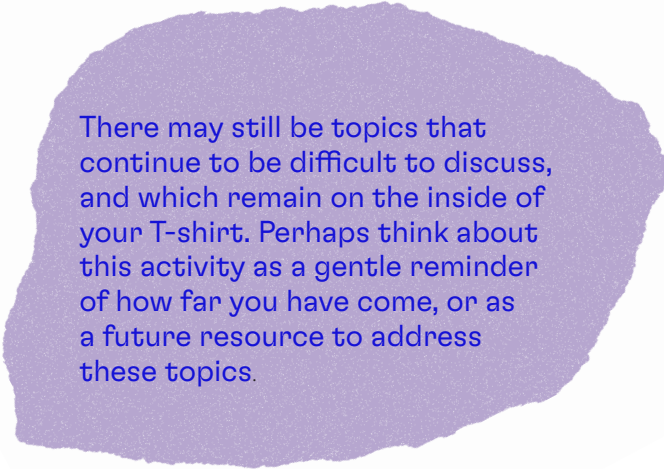
c) What has enabled you to talk about these subjects more openly?

Write your response onto the blank side of each relevant tag. Then fix each tag to the T-shirt, using the remaining velcro dots, ensuring that these statements are face up.

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d) What support or additional opportunities do you feel might enable people diagnosed with primary breast cancer to more easily share their experiences with others?

Please write your response directly onto the outside of the garment, using the fabric pen provided.



There may still be topics that continue to be difficult to discuss, and which remain on the inside of your T-shirt. Perhaps think about this activity as a gentle reminder of how far you have come, or as a future resource to address these topics.

These exercises also mark the end of the activity pack and at this point, it might be useful to touch base with your 'buddy' or with Nicola Cunningham, if there are any further things that you would like to talk about.

To conclude...

Place your garment, **without removing any of the tags**, into the Returns Package, ready to send back to the study researcher. The returns guide on pg.62 will help you to prepare your package ready for collection by courier.

Now take a few moments to complete the feedback form overleaf.

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Feedback

This form will take approx. 5-10mins to complete.

1. How did you find doing these exercises?
(You may want to consider things like their duration, clarity or relevance to you)

2. What did you enjoy most about these exercises?

3. What did you enjoy least?

(Do you have any recommendations for how the exercises can be improved?)

4. What are your thoughts on the concept for these exercises?
i.e. **Writing on the inside and outside of a garment to reflect on private and public thoughts.**

5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?

You have now completed all of the five activities. Ensure that you take some time for yourself, to do something that makes you feel good!

Returns

It's time to prepare your Returns Package ready for collection.

Returns Package

In your activity box you will find the following materials...

- A large, orange, padded envelope
- An extra large, white, self seal postal bag
- Return address labels.

Place your completed activity book and any accompanying items that you've made (collage, lilac T-shirt) into the large orange envelope provided.

Don't forget to also remove the memory card from your camera placing it into the small orange envelope in your camera box. Seal and add this to the Returns Package.

Now place everything into the large white postal bag, sealing it tightly and contact Rhian to arrange collection by courier.

Follow-up Focus Group

We'll all be meeting, within a week or so, to discuss your experiences of the creative activities in this book. Rhian will be in touch shortly to organise this with you.



Be sure to keep hold of your digital camera and any art materials or equipment that you haven't used. This is a gift to say a huge thank you for giving your time and creative energy to the study.

Thank You!



Other useful organisations

Should you require any further support, the following charities offer useful advice and information.

Breast Cancer Haven www.breastcancerhaven.org.uk

Breast Cancer Now www.breastcancernow.org

Penny Brohn www.pennybrohn.org.uk

Look Good Feel Better www.lookgoodfeelbetter.co.uk

Future Dreams www.futuredreams.org.uk

Maggies www.maggies.org

Macmillan Cancer Support www.macmillan.org.uk

Recollective Threads, 2021
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G1 5PD. Home to Good Press and
Lunchtime Gallery

#

(Please insert your item number here eg. 1-9)

1. Wardrobe Mapping

1. Please write a brief description of your garment here (eg. grey spotted blouse)

2. What significant moment does this item represent to you and your diagnosis, treatment or recovery?

3. Why is this item significant to you?

4. Adapt

1. Please write a brief description of your garment here (eg. grey spotted blouse)

2. What changes have you made to this garment since diagnosis and/or treatment?

3. Why have you made these changes?

APPENDIX B – ETHICAL APPROVAL

APPENDIX B.1. ETHICAL APPROVAL UNIVERSITY OF THE ARTS LONDON

ual:

To Whom it May Concern:

Ref ID: 07208287

Date: 27 Sep 2021

Dear Sir/Madam,

I'm writing to confirm the ethics approval status of Rhian Solomon's PhD project, which she is studying at the London College of Fashion (LCF).

On the date of the **29 June 2021** the LCF Research Degrees Sub-Committee (RDSC) reviewed Rhian's application for ethics approval and deemed it to be **approved with minimal risk**. This has subsequently been ratified the University Research Ethics Sub-Committee.

Rhian's studies commenced on **29 Sep 2014** and are due to conclude by the end of **30 Sep 2023**. During this time, if it is known that the project has changed and the previous application for ethics approval no longer stands accurate, Rhian will need to submit a new application for ethics approval with the LCF CRDSC.

Yours faithfully

Daniel Taylor
LCF CRDSC Clerk



Professor Felicity Colman
RESC Chair

PROF. FELICITY COLMAN

APPENDIX B.2. LETTER OF SUPPORT – BREAST CANCER HAVEN



PhD candidate – Rhian Solomon
University of the Arts, London – London College of Fashion
Supervisory Team – Prof. Jane Harris (DOS) and Prof. Sandy Black
Funders – The Arts and Humanities Research Council

This is a letter to approve the involvement and support from Breast Cancer Haven, London for the following PhD project.

PhD title –

How can craft inform communication between people who have undergone complex breast reconstruction and breast reconstruction surgeons about experiences of surgical procedure?

Breast Cancer Haven agree to support the study in the following ways.

1. Providing a designated space to run 2 x 1.5hr workshops at Breast Cancer Haven, Effie Road, Fulham, London, SW6 1TB – anticipated to run Apr-Jun 2018. One workshop per month. (An appropriate time and date will be agreed between Breast Cancer Haven, London and the student researcher).

2. Providing a designated space to run post workshop co-reflective interviews with workshop participants at Breast Cancer Haven, Effie Road, Fulham, London, SW6 1TB – anticipated to run Apr-Jun 2018. This is expected to be between 4-6 interviews in total/until data saturation is achieved.

3. Supporting in the recruitment of service users of Breast Cancer Haven, Effie Road, Fulham, London, SW6 1TB – The researcher is seeking to recruit through the charities networks, 8-10 individuals who have undergone complex breast reconstruction surgery (DIEP, TRAM or Latissimus Dorsi procedures) as treatment for primary breast cancer. Promotional materials for these activities (inc posters and flyers) have been drafted and designed by the researcher to be approved by Breast Cancer Haven, Effie Road, Fulham London centre manager and research lead. Where possible, an e-invite will also be electronically distributed to the Breast Cancer Haven networks of service users and breast reconstruction surgeons.

4. Providing participant emotional support – Breast Cancer Haven, London will recruit (from their staff members) a cancer support specialist to be present during each of the two 1.5hr workshops. To provide emotional support to participants and the study researcher, in the event that any participants should experience discomfort taking part in the sessions. A referral telephone number will also be provided by Breast Cancer Haven and by the researcher to direct participants to additional support, should this be required. The

researcher will take full responsibility for paying for the service of a cancer support specialist during 2 x workshops at a fee of 25.00 ph. The researcher will also cover the cost of travel expenses for participants to attend research workshops.

Breast Cancer Haven Clinical and Research Director

(NAME) Barbara Hoff agrees that

She can support this study upon approval of University of the Arts London research ethics

She agrees to providing the above provision to the study.

Research Lead

Signed –

Date –

Breast Cancer Haven, Fulham Centre Manager

(NAME) Nicola Cunningham agrees that

She can support this study upon approval of University of the Arts London research ethics

She agrees to providing the above provision to the study.

Signed – [Signature]

Date – 6th December 2017

If you require any further information regarding this study or have any further queries please contact the college research office.

Research Office, University of the Arts London, London College of Fashion, 20 John Princes Street, London, W1G 0BJ, 0207 5147400.

APPENDIX C - SAMPLING, RECRUITMENT AND CONSENT

APPENDIX C.1. INCLUSION CRITERIA

PHASE 1

Workshop Facilitator Interviewees Taking part in semi-structured interviews	
Sample Size 4	
Practice inclusion criteria	
Context of Facilitation	Apply their methods in complex health contexts
	Apply their methods in collective, facilitated workshop settings
Methodological Approach	Combine Making and Cloth(ing) in the design and deployment of their methods.
	Explore the relations between bodies and materials in the design of their methods.
Expertise	Are currently practicing and have established Making and Cloth(ing)-led Facilitation practices.
Female and Male	
Age 18+	
Proficient in the use of English language	

PHASE 2

<p>Service User Participants Taking part in Wardrobe Probe + Group Workshop</p>	<p>Clinician Participants Taking part in Group Workshop</p>
<p>Sample size Maximum 8 This small sample size was dictated by the design research methods being developed and tested which produced rich, thick qualitative data.</p>	<p>Sample size Maximum 4 It was important for the study researcher to maintain equal numbers of service providers/designers with service users, (see below), so as not to create an imbalance of perspectives during an intimate, group workshop at London College of Fashion.</p>
<p>Inclusion Criteria</p>	<p>Inclusion Criteria</p>
<p>Treatment type Have undergone breast reconstruction, as treatment for breast cancer, at least 6 months ago (To include Latissimus Dorsi, TRAM flap, DIEP, SIEA, SGAP, LICAP, TAP, Fat Grafting) and participants carrying BRCA1 or 2 genes. Have received treatment a minimum of 6 months prior to the study. *This criteria was developed in consultation with Breast Cancer Haven research team.</p>	<p>Clinical specialism The study was promoted to a wide spectrum of clinicians providing breast cancer services -Clinical Oncologists -Breast cancer Clinical Nurse Specialists -Breast reconstruction plastic surgeons -Therapeutic specialists - including physio, massage, -Medical tattooists</p>
<p>Female and Male Breast cancer is more prevalent within women than men (55,000 women diagnosed per year and 400 men (Breast Cancer Now, 2024) and so higher numbers of women were expected to take part.</p>	<p>Female and Male Whilst some of these select professions are disproportionately practiced by differing sexes the aim was to have a combination taking part in the study.</p>
<p>Age 18+ No upper age limit to ensure inclusivity but also because breast cancer tends to affect women in later phases of their life.</p>	<p>Age 18+</p>
<p>Based in Greater London</p>	<p>Based in Greater London and the South East</p>
<p>Proficient in use of English language</p>	<p>Proficient in use of English language</p>
	<p>Registered to practice and currently practicing</p>

Service Designers/User Researchers in Healthcare Taking part in Group Workshop
Sample Size
Maximum 4 It was important for the study researcher to maintain equal numbers of service providers/designers with service users (see above), so as not to create an imbalance of perspectives during an intimate group workshop at London College of Fashion.
Inclusion criteria
Professional specialism User Research in health Service Design in health
Female and Male
Age 18+
Based in Greater London
Proficient in use of English language

APPENDIX C.2. PARTICIPANT INFORMATION SHEET – FACILITATOR INTERVIEWEES

Participant Information Sheet Interview and Recording

Rhian Solomon, PhD research student at University of the Arts, London (London College of Fashion) would like to invite you to take part in a PhD research study.

Please read the following information before deciding if you would like to take part and reply to Rhian Solomon if you would like any further information. See contact details below.

If you wish to participate, you should keep this information sheet, sign the consent form provided as a sign of consent to participate.

This study is exploring

Designer Facilitator: The Body as a meeting place and materials as a medium for enhancing communication between people who have undergone breast reconstruction and breast reconstruction surgeons.

The study researcher would like to invite you to take part in a 1 hr interview.

The aim of this interview is to document your practice and experience of opening dialogues between groups of people, through the use of materials and/or objects.

During the interview you will be asked a series of questions about your approaches to your practice.

An audio recording will be made of this interview.

All interviews will be conducted within a space that is suitable for yourself, the interviewee, and for recording requirements. Where possible, the researcher would prefer to visit practitioners within their place of work.

Your role within this study will help to..

- Inform understanding of how materials and/or objects might be used to develop communication between people who have undergone complex breast reconstruction and breast reconstruction surgeons, to understand lived experiences of breast cancer.

Please note: Participation in this study is voluntary. Participants are able to cease involvement at any moment and without any consequence.

What will happen if you agree to participate?

1. You will be asked to sign a consent form if you are willing to participate
2. You will be asked to participate in a 1hr interview with the researcher on an agreed date – this will be recorded for research purposes.
3. You can choose to receive information about future events and workshops related to this study – please tick the allocated box on consent form to request this information.

The study will offer participants the opportunity to

- Shape new design methods that inform communication between clinicians and people who have undergone complex surgery.
- Shape new design methods that could be used in the design of future healthcare services.

The findings from these interviews will provide a review of creative practices that enhance communication between diverse communities.

Confidentiality and anonymity

The audio-recordings made during the interviews will be securely locked in cabinets and password protected filing systems on a computer at University of the Arts London (London College of Fashion). The transcribed interview scripts will remain confidential. The information will be analysed by the researcher and reviewed by the researcher's supervisory team. With your consent, anonymised confidential documents may be used for publication, research, and teaching purposes, and verbatim quotations may be included. Such quotations will be used to describe specific experiences. The study will be conducted in accordance with The University of the Arts, London Code of Ethics and Research Governance.

Concerns that this study raises

Protocols have been followed in line with University of the Arts, London Code of Ethics to ensure there is a minimal impact on those participating.

Should you have any questions or concerns about taking part in this study please contact:

Research Office, UAL, London College of Fashion, 20 John Princes Street, London, W1G 0BJ, 0207 5147400

Further information

For clarification of any of these details, please contact the researcher on this project:

Rhian Solomon r.solomon1@arts.ac.uk or mail@rhiansolomon.co.uk

I would like to thank you for your time in reading this document.

APPENDIX C.3. CONSENT FORM – FACILITATOR INTERVIEWEES

Participant Consent

For research use only: Participant number

Project Title

Designer Facilitator: The Body as a meeting place and materials as a medium for enhancing communication between people who have undergone complex breast reconstruction and breast reconstruction surgeons.

PhD Student Researcher – Rhian Solomon

Research Centre: University of the Arts, London, London College of Fashion,
20 John Princes Street, London, W1G 0BJ

Please ***initial all of the statements in the boxes below to signify your consent.***

1. I confirm that I have read, understood and been given a copy of the information sheet for the project *Designer Facilitator* and have had the opportunity to ask questions.

2. I agree to take part in the project *Designer Facilitator* by taking part in a 1hr interview conducted at one of the following venues – Please tick applicable
 1. Interviewee's Studio/Office space
 2. A bookable room at London College of Fashion
 3. A suitable agreed alternative space TA
(To be discussed with Rhian Solomon)

3. I agree to the recording of my voice in the conversation during this interview.

4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason or at any detriment to myself.

5. I understand that the information gathered during the audio recordings of the interview will be transcribed.

5. I understand that the PhD student researcher who will conduct the interview, will be taking notes, and there is the possibility of use of quotations anonymously from these recordings and such notes - the use of which will be agreed with you as the participant upon use.

6. I understand that information gathered will be read and analysed by the PhD student researcher – Rhian Solomon and her supervisory team at London College of Fashion.

7. I agree to anonymised information being used for research purposes and potentially in publication (in whole or in part) in peer-reviewed academic journals and in other forms of dissemination such as academic presentations.

8. I agree to anonymised information being used for teaching purposes and educational materials (in whole or in part) in appropriate formats.

9. I would like to receive a summary of the findings of this study.

Your name: Teresa Almeida

Date: 23/04/2018

Address: [REDACTED]

Telephone Number: [REDACTED]

Email: [REDACTED]

Signature: 

Completed consent forms will be filed in locked cabinets at University of the Arts, London, London College of Fashion,
20 John Princes Street, London, W1G 0BJ

APPENDIX C.4. PARTICIPANT INFORMATION SHEET – SERVICE USERS

Service User Information Sheet Activities 1, 2 + 3

PhD Title – Design Facilitation: Towards clothing-centred approaches to advancing collaborations in healthcare.

Rhian Solomon, PhD student at University of the Arts London, would like to invite you to take part in a PhD research study.

Please read the following information and contact Rhian directly if you have any further questions. T - 07800 907380 E - r.solomon1@arts.ac.uk W - www.recollective-threads.com

All research activities in this study will follow strict UK government guidelines for reducing any Covid-19 infection risks. This document outlines detailed measures put in place, by the study researcher, to adhere to these guidelines.

Please check that you meet the criteria for taking part in this study

Study Inclusion Criteria

Age 18+

Living in Greater London

Proficient in the use of English Language

Female or male

Have undergone breast reconstruction as treatment for primary breast cancer, at least 6 months ago (To include Latissimus Dorsi, TRAM flap, DIEP, SIEA, SGAP, LICAP, TAP, Fat Grafting) *including participants carrying BRCA1 or 2 genes.

Study Exclusion Criteria

People carrying BRCA1 or BRCA2 genes who have not been diagnosed or treated for primary breast cancer

People diagnosed or treated for secondary breast cancer.

People who are currently experiencing psychosis.

This research study is..

- Developing creative methods to be used in the design of future healthcare services - emphasizing the importance of understanding service user experience in informing successful design outcomes.
- Designing a set of tools which can be used by participants to reflect on and share their experience of primary breast cancer; with designers and clinicians during co-design activities.

* As a thank you for taking part in this study, all participants will receive a digital camera.

* Travel and postal costs will be covered by the study researcher.

* The study researcher, Rhian Solomon, will be available (online/via telephone) to answer any practical questions about the activities.

*A designated cancer support specialist will also be available (online/via telephone) to provide confidential emotional support to participants if/where needed.

www.recollective-threads.com/support.

*Care will be taken to ensure that service user participants are not known to clinician participants prior to taking part in the study.

We would like to invite you to take part in a series of creative activities which will require, in total, approx. 6-8 hours of your time, spread across a 7 month period (**Nov 2021 - May 2022**).

Activity 1 (Nov 2021) - 5 x 45 minute creative, home-based activities

Activity 2 (Dec 2021) - 1.5hr focus group (online)

Activity 3 (May 2022) - 2hr creative workshop (in person - *Covid dependent) at London College of Fashion. *This activity will only take place when there is a low risk of Covid-19 Infection **or** when UK government guidance allows for workshop participants to meet safely in a space, following social distancing measures.

Where possible, the study researcher asks that participants are able to take part in all 3 stages of the research project outlined above (Activities 1-3) as opposed to individual elements. This is to assess participant's evolving experiences of taking part in the study, throughout.

In detail...

Activity 1 - 5 x Home-based, creative exercises

This activity will involve using photography, word association and collage techniques to think about your wardrobe in a variety of creative ways; considering any changes that may have occurred before, during and following your treatment for primary breast cancer.

This activity would involve...

- An activity pack will be couriered by the study researcher to your preferred postal address. To minimise any risk of Covid infection, the package will have been prepared by the study researcher whilst wearing gloves and mask, and all contents will be sanitised. You will be encouraged to 'quarantine' the package for 7 days on receipt, before opening it.
- The study researcher will run a short introduction to using the activity pack with all participants, online, at an appropriate date and time, to provide an opportunity for any questions to be asked about the study.
- At your own pace, using the materials provided, you will undertake 5 creative activities across a period of 4 weeks.
- When you have finished the activity pack, you will be asked to complete a short feedback form which will allow the study researcher to understand your experience of using it. The questions in this form will ask you to consider the pitch, relevance and design of activities.
- All content that you create through these creative activities will temporarily be returned to the study researcher for analysis, who will organise for a courier to collect your activity pack from your home. The cost of this will be covered by the study researcher. This content will be returned to you, to keep, within 7 months of you completing the activities - by 21st May 2022. Again, the package will be prepared, as above, to minimise any risk of Covid infection.

Activity 2 - 1.5hr Focus group (online)

This activity will bring together all (x8) participants from Activity 1 to briefly discuss experiences of using the home-based activities as well as the artefacts that have been created.

This activity would involve...

- The study researcher will contact you by email/telephone to arrange a date and time to conduct the focus group.
- A 1.5hr focus group will take place (online). Attendees will include all participants of activity 1, the study researcher, Rhian Solomon, and a cancer support specialist.
- This focus group will be video and audio recorded for data analysis.
- Information collected through the session will inform the design of the following stage of the research (Activity 3 outlined below).
- No additional Covid measures are required for this activity, as there is no risk of infection.

Activity 3 - 2hr Creative workshop (In person - Covid dependant) at London College of Fashion, John Princes Street, W1G 0BJ. During this activity, artefacts and methods developed and discussed by participants during Activities 1 and 2 will be featured, anonymously, and used to open conversations between participants, clinicians and designers to explore of experiences of breast cancer.

*Clinician participants will be recruited to the study for this phase of the study only. Clinicians will be emailed by Breast Cancer Haven centre staff to recruit. They will be asked to read the project information and complete a consent form prior to taking part. 6-8 clinicians will be recruited in total, who will include Breast Reconstruction Plastic Surgeons, Breast Care Clinical Nurse Specialists, Medical and Clinical Oncologists. The consent process will ensure that participants are not known to one another, prior to taking part in the study.

This activity would involve...

- A face-to-face workshop, consisting of participants from Activities 1 and 2, plus the newly recruited clinicians, will be run at a date and time organised with all participants. The study researcher will lead this workshop.
- This session will be audio and video recorded for data analysis.
- You will be asked to complete a short, feedback form, as part of this event which will be distributed and collected by the study researcher at the end of the session. The questions in this form will ask you to reflect on your experience of the creative activities in the workshop.

To minimise the risk of Covid infection for this activity..

- Participants will be recruited from the same geographical region (Greater London).
- The workshop will take place in central London, at London College of Fashion (20 John Princes Street, W1G 0BJ) to ease travel duration for all participants.
- The venue for the workshop will be cleaned prior to and following the event taking place.
- The venue will be large enough to safely host all participants whilst socially distancing.
- The venue will be well ventilated.
- All materials will be disinfected. There will be no shared materials/equipment - participants will each have an individual equipment pack.
- All participants, including the study researcher and cancer support specialist, will be requested to wear a well-fitting mask throughout the workshop (the study researcher will provide these on arrival).
- Adequate hand sanitizing facilities will be available throughout the event.

Findings from all activities (1-3) will enable the study researcher to propose a set of methods to inform the design of future healthcare services.

If you would like to take part in this study..

- Please get in touch with the study researcher (Rhian Solomon) using the contact information on this form or on the email [contact form](#) at www.recollective-threads.com. The study researcher will contact you directly, using the telephone number/email address that you have provided, to answer any questions that you may have and to confirm whether you would like to take part in the study.
- You will be asked to complete a project consent form, which must be returned before taking part in the study. As part of this process, you will be required to provide a postal address, so that research activity packs can be mailed to your home/preferred delivery address. *Please refer to details on the following page regarding data protection and confidentiality.
- As part of the consent process for these activities you can choose to receive a summary of the research findings. Please tick the box provided, as appropriate, on the consent form.
- Should these activities raise any concerns to yourself, contact information is provided, offering a dedicated cancer support service (www.recollective-threads.com/support).

- If you feel that you no longer wish to take part in this study, you are free to withdraw at any time until the 31st August 2022. This will have no consequence to you personally or to the care that you receive. Please inform the study researcher directly, to remove your data from the study (r.solomon1@arts.ac.uk).

Possible benefits of taking part

Your role in this PhD study will help to..

- Develop design methods which emphasize the importance of understanding service user experience in the redesign of health services.
- Develop design methods which enable people to reflect on and share their experience of primary breast cancer with others.

The study will offer participants the opportunity to..

- Share and reflect on their experience with individuals who have undergone similar treatments for primary breast cancer.
- Explore creative methods which may inform communication between service users, clinicians and designers during the design of health services.
- Raise awareness to others about the impact of primary breast cancer on people's lives.
- Have their voice heard in a research and healthcare setting.

Confidentiality and anonymity

Any artefacts that you create during these activities will remain your property. Any research data captured during the above activities, using audio recording, will be transcribed. All documents will be anonymized and will remain confidential. A hard copy of all anonymised research data will be downloaded and kept securely in a locked cabinet in the study researcher's home - Only the study researcher will hold the key to this. A digital copy of research data will also be stored in password protected files on the study researchers personal computer. This computer will be stored in a locked cabinet in the study researcher's home. All digital files containing identifying personal data (including your name, postal address, contact details) will be encrypted and password protected and will be stored in files, separate to research data on the study researchers computer. All identifying personal data will be permanently destroyed by **31st August 2022**.

Anonymised research data will be analysed solely by the study researcher (Rhian Solomon) and reviewed by the study researcher's supervisory team (Professor Jane Harris and Professor Sandy Black). With your consent, research findings may be used for publication, research, and teaching purposes and may include verbatim quotes. These quotes will be used to describe specific experiences but will not be linked to any participant, personally. The study will be conducted in accordance with University of the Arts London, Code of Ethics and Research Governance to ensure that there is minimal impact on those participating. All research data will be permanently destroyed by **31st Oct 2028**.

Should you have any concerns about taking part in this study please contact:
researchethics@arts.ac.uk
Research Office, University of the Arts London, London College of Fashion.
20 John Princes Street, London, W1G 0BJ.

Thank you for taking the time to read this information

APPENDIX C.5. CONSENT FORM – SERVICE USERS

Patient Consent Form Activities 1, 2 + 3

For research use only: Participant #

P2

PhD Title – Design Facilitation: Towards clothing-centred approaches to advancing collaborations in healthcare.

PhD Student Researcher – Rhian Solomon
Research Centre - University of the Arts, London, London College of Fashion,
20 John Princes Street, London, W1G 0BJ

Please initial all of the relevant statements in the boxes below to signify your consent.

1. I confirm that I have read and understood the participant information sheet for research Activities (1-3) of the above project and have had the opportunity to ask questions.

2. I agree to take part in the study by -
 - Activity 1 - Home-based activity pack**
 - Completing a series of short creative activities in which I will select worn items (garments, accessories, footwear etc) from my wardrobe and consider how they have changed over time - using collage and photographic techniques.
 - Completing a short written feedback form.
 - Activity 2 - Focus Group**
 - Attending a 1.5hr focus group (online) to discuss, with other study participants, artefacts that I have created during Activity 1, as well as ideas for sharing these outcomes with others (during Activity 3 - Group workshop).
 - Activity 3 - Group Workshop**
 - Attending a 2hr group workshop (in person - *covid dependant) at an appropriate date and time, at London College of Fashion. *This activity will only take place when there is a low risk of Covid-19 Infection or may occur online if it is not possible to meet in person.
 - Completing a short written feedback form.

- 3a. I agree to the study researcher audio recording my voice during the focus group (Activity 2) and taking notes.
- 3b. I agree to the study researcher video recording the focus group (Activity 2).
- 3c. I agree to the study researcher audio recording my voice during the group workshop and taking notes (Activity 3).

- 3d. I agree to the study researcher video recording during the group workshop (Activity 3).
4. I understand that all information gathered through the research activities outlined on this form will be anonymised - Eg. Audio recordings of the focus group (Activity 2) and workshop

(Activity 3) will be transcribed, visual identities will be obscured in video footage (Activity 3). Participants will be allocated study ID's and fictitious names across all data sets, any identifying personal data (names, contact details) will be removed from consent/feedback forms (Activities 1+3). This information will be permanently destroyed by 31st August 2022.

5. I understand that all information gathered through the research activities outlined on this form will be downloaded into a hard copy paper version which will be stored in a locked cabinet. Only the study researcher will hold the key to this. Both digital and hard copy versions of research data will be held by the study researcher until 31st Oct 2028. At which point this data will be permanently destroyed.
6. I understand that information gathered through all of the research activities outlined on this form will be read and analysed by the study researcher (Rhian Solomon) and reviewed by her supervisory team (Prof. Jane Harris and Prof. Sandy Black) at University of the Arts London - London College of Fashion.
7. I agree to anonymised information being used for research purposes and publication (in whole or in part) in peer-reviewed academic journals and in other forms of dissemination such as academic presentations and exhibitions. This may include quotations selected from focus group+ workshop discussions, and from completed feedback forms (Activities 1, 2 + 3), images of artefacts that I have created (Activity 1), film stills taken from workshop video footage (Activity 3),
8. I agree to anonymised information being used for teaching purposes and educational materials (in whole or in part) in appropriate formats such as academic lectures and creative workshops.
9. I understand that my participation is voluntary and that I am free to withdraw at any point until 31st Aug 2022. I will not need to give any reason for my withdrawal and this will be without consequence to me personally or to the care that I receive.
10. I would like to receive a summary of the findings of this study.

Your contact details

Name:

Email address:

Contact telephone number:

Postal address: (*Materials for Activity 1 will be posted to this address)

Signature: [REDACTED]

Date: 31/08/2021.

In order to ensure that study participants are not known to one another in Activity 3 of this study (Group workshop with clinicians), please can you complete the following..

The name(s) of the clinicians who you have been treated by: (To include Breast Reconstruction Plastic Surgeons, Breast Cancer Clinical Nurse Specialists, Medical or Clinical Oncologists)

[REDACTED]

[REDACTED]

Please return this form to the Study Researcher, Rhian Solomon
By email r.solomon1@arts.ac.uk Or
By post to [REDACTED]

Thank you for completing this form

APPENDIX C.6. PARTICIPANT INFORMATION SHEET – DESIGNERS/CLINICIANS

Clinician/Designer Information Sheet Activity 3

PhD Title – Design Facilitation: Towards clothing-centred approaches to advancing collaborations in healthcare.

Rhian Solomon, PhD student at University of the Arts London, would like to invite you to take part in a research study.

Please read the following information and contact Rhian directly if you have any further questions.

T - 07800 907380 E - r.solomon1@arts.ac.uk W - www.recollective-threads.com

This research activity will follow strict UK government guidelines for reducing Covid-19 infection risks. This document outlines detailed measures put in place by the study researcher, to adhere to these guidelines.

Please, check that you meet the criteria for taking part in this study

Study Inclusion criteria

Based in Greater London or the SE England

Registered to practice

Currently practicing as a Breast Cancer Clinical Nurse Specialist, Complimentary or Alternative therapist, Health Service Designer, User Researcher, Breast Reconstruction Plastic Surgeon, Medical or Clinical Oncologist,

This research study is...

- Developing creative methods to be used in the design of future healthcare services - emphasizing the role of understanding service user experience in informing successful design outcomes.
- Designing a set of creative methods which can be used by service users to reflect on and share their experience of primary breast cancer; with designers and clinicians during co-design activities.

Activity 3 - Creative workshop 21st May 2022 (*in person - Covid dependant)

We would like to invite you to take part in a 2hr creative workshop at London College of Fashion. Participants to this workshop will include people who have been treated for primary breast cancer (who have also taken part in earlier phases of this research project - Activities 1+2), Health Service Designers, Breast Cancer Clinical Nurse Specialists, Breast Reconstruction Plastic Surgeons, Medical and Clinical Oncologists. The aim of this workshop is to explore experiences of breast cancer, using artefacts and creative methods.

This activity would involve...

- Taking part in a 2hr creative workshop at London College of Fashion, 20 John Princes Street, London W1G OBJ.
- Completing a feedback form. The questions in this form will ask you to reflect on your experience of the creative activities in the workshop.
- The session will be audio and video recorded for data analysis.
- Refreshments will be provided on the day.

Findings from this activity will enable the study researcher to propose a set of methods to be used in the co-design of future healthcare services.

Your role in this PhD study will help to...

- Develop design methods that emphasize the role of understanding service user experience in the design of health services.
- Develop design methods that enable people to reflect on and share their experience of primary breast cancer with others.

The study will offer clinician/service designer participants the opportunity to...

- Learn about service user experience in new ways.
- Explore creative methods as a means opening discussions between service users, clinicians and designers during the design of health services.

* All travel costs will be reimbursed by the study researcher.

* Care will be taken to ensure that participants are not known to one another prior to taking part in the study.

* The study researcher, Rhian Solomon, will be available before the workshop (online/via telephone/in person) to answer any practical questions about the activity.

* A designated cancer support specialist will be available (in person) during the workshop, to discuss difficult emotions that may arise.

*This activity will only take place when there is a low risk of Covid-19 Infection **or** when UK government guidance allows for workshop participants to meet safely in a space, following social distancing measures.

To minimise the risk of Covid infection for this activity..

- The venue for the workshop will be cleaned prior to and following the event taking place. (This venue will be large enough to safely host all participants)
- The venue will be well ventilated.
- All materials will be disinfected.
- All participants, including the study researcher and cancer support specialist, will be requested to wear a well-fitting mask throughout the workshop (the study researcher will provide these on arrival).
- Adequate hand sanitizing facilities will be available throughout the event.

If you would like to take part in this study..

- Please get in touch with the study researcher (Rhian Solomon) using the contact information on this form or on the email [contact form](#) at www.recollective-threads.com. The study researcher will contact you, using the telephone number/email address that you have provided, to answer any questions that you may have and to ask whether you would like to take part in the study.
- Taking part requires the completion of a project consent form, which needs to be returned before the study begins.
- Should this activity raise any concerns to you, contact information is provided, offering a dedicated cancer support service (www.recollective-threads.com/support).
- If at any point you feel that you no longer wish to take part in this study, you are free to withdraw until the 31st August 2022. This will have no consequence to you personally. Please inform the study researcher directly, to remove your data from the study (r.solomon1@arts.ac.uk).
- As part of the consent process for this activity you can choose to receive a summary of the research findings. Please tick the box provided on the consent form, as appropriate.

Confidentiality and anonymity

Video and audio-recordings which capture the creative activities and conversations during this workshop will be transcribed. All documents will be anonymized and will remain confidential. A hard copy of all transcription documents and accompanying research data will be downloaded and kept securely in a locked cabinet in the study researchers home - only the study researcher will hold the key to this. A digital copy of research data will be stored in password protected files on the study researchers Personal Computer. This computer will be stored in a locked cabinet in the study researcher's home. All digital files containing identifying personal data (including your name, contact details) will be encrypted and password protected and will be stored in files, separate to research data, on the study researchers computer. All identifying personal data will be permanently destroyed by **31st August 2022**.

This information will be analysed solely by the study researcher and reviewed by the researcher's supervisory team (Professor Jane Harris and Professor Sandy Black). With your consent, research findings may be used for publication, research, and teaching purposes and may include verbatim quotes. These quotes will be used to describe specific experiences but will not be linked to any individual participant. The study will be conducted in accordance with University of the Arts London, Code of Ethics and Research Governance to ensure that there is minimal impact on those participating. All research data will be permanently destroyed by **31st Oct 2028**.

Should you have any concerns about taking part in this study please contact: researchethics@arts.ac.uk

**Research Office, University of the Arts London, London College of Fashion.
20 John Princes Street, London, W1G 0BJ.**

Thank you for taking the time to read this information

APPENDIX C.7. CONSENT FORM – DESIGNERS

Designer Consent Form Activity 3

For research use only: Participant #

P7

PhD Title – Design Facilitation: Towards clothing-centred approaches to advancing collaborations in healthcare.

PhD Student Researcher – Rhian Solomon

**Research Centre - University of the Arts, London, London College of Fashion,
20 John Princes Street, London, W1G 0BJ**

Please initial all of the relevant statements in the boxes below to signify your consent.

1. I confirm that I have read and understood the participant information sheet for research Activity 3 (Group workshop) of the above project and have had the opportunity to ask questions.
2. I agree to take part in the study by..
 - Attending a 2hr group workshop (21st May 2022) at London College of Fashion, during which service users, clinicians and designers will discuss future opportunities for designing breast cancer services. *This activity will only take place when there is a low risk of Covid-19 Infection or when UK government guidance allows for workshop participants to meet safely in a space, following social distancing measures. If infection rates remain high, this activity may also occur online.
 - Completing a written feedback form to reflect on my experience of this workshop.
- 3a. I agree to the study researcher audio recording my voice during the workshop and taking notes.
- 3b. I agree to the study researcher video recording the workshop.
4. I understand that all information gathered through this research activity will be anonymised- Eg. Audio recordings of the workshop will be transcribed, visual identities will be obscured. Participants will be allocated pseudonyms and study ID's across all data sets. Any identifying personal data (names, contact details) will be redacted by the researcher and will be permanently destroyed by 31st Aug 2022.
5. I understand that all information gathered in this research activity will be downloaded into a hard copy paper version which will be stored in a locked cabinet. Only the study researcher will hold the key to this. Both digital and hard copy versions of research data will be held by the study researcher until 31st Oct 2028. At which point all research data will be permanently destroyed.
6. I understand that information gathered through this activity will be read and analysed by the study researcher (Rhian Solomon) and reviewed by her supervisory team (Prof. Jane Harris and Prof. Sandy Black) at University of the Arts London.

7. I agree to anonymised information being used for research purposes and publication (in whole or in part) in peer-reviewed academic journals and in other forms of dissemination such as academic presentations and exhibitions. This may include film stills taken from workshop video footage, quotations selected from workshop discussions and completed feedback forms.
8. I agree to anonymised information being used for teaching purposes and educational materials (in whole or in part) in appropriate formats such as academic lectures and creative workshops.
9. I understand that my participation in this study is voluntary and that I am free to withdraw at any point until 31st Aug 2022. I will not need to give any reason and this will be without consequence to me personally.
10. I would like to receive a summary of the findings of this study.

Your contact details

Name: [REDACTED]

Professional Specialism(s): USER RESEARCHER

Email address: [REDACTED]

Contact telephone number : [REDACTED]

Signature: PM

Date: 12/05/2022

Please return this form to the Study Researcher, Rhian Solomon
By email r.solomon1@arts.ac.uk

Thank you for completing this form

APPENDIX C.8. CONSENT FORM – CLINICIANS

Clinician Consent Form Activity 3

For research use only: Participant #

P10

PhD Title – Design Facilitation: Towards clothing-centred approaches to advancing collaborations in healthcare.

PhD Student Researcher – Rhian Solomon
Research Centre - University of the Arts, London, London College of Fashion,
20 John Princes Street, London, W1G 0BJ

Please initial all of the relevant statements in the boxes below to signify your consent.

1. I confirm that I have read and understood the participant information sheet for research Activity 3 (Group workshop) of the above project and have had the opportunity to ask questions.

2. I agree to take part in the study by..
 - Attending a 2hr group workshop at an appropriate date and time to suit, at London College of Fashion, during which service users, clinicians and designers will discuss future opportunities for designing breast cancer services. *This activity will only take place when there is a low risk of Covid-19 Infection or when UK government guidance allows for workshop participants to meet safely in a space, following social distancing measures. If infection rates remain high, this activity may also occur online.

 - Completing a written feedback form to reflect on my experience of this workshop.

- 3a. I agree to the study researcher audio recording my voice during the workshop and taking notes.

- 3b. I agree to the study researcher video recording the workshop.

4. I understand that all information gathered through this research activity will be anonymised- Eg. Audio recordings of the workshop will be transcribed, visual identities will be obscured. Participants will be allocated pseudonyms and study ID's across all data sets. Any identifying personal data (names, contact details) will be redacted by the researcher and will be permanently destroyed by 31st Aug 2022.

5. I understand that all information gathered in this research activity will be downloaded into a hard copy paper version which will be stored in a locked cabinet. Only the study researcher will hold the key to this. Both digital and hard copy versions of research data will be held by the study researcher until 31st Oct 2028. At which point all research data will be permanently destroyed.

6. I understand that information gathered through this activity will be read and analysed by the study researcher (Rhian Solomon) and reviewed by her supervisory team (Prof. Jane Harris and Prof. Sandy Black) at University of the Arts London.

7. I agree to anonymised information being used for research purposes and publication (in whole or in part) in peer-reviewed academic journals and in other forms of dissemination such as academic presentations and exhibitions. This may include film stills taken from workshop video footage, quotations selected from workshop discussions and completed feedback forms.
8. I agree to anonymised information being used for teaching purposes and educational materials (in whole or in part) in appropriate formats such as academic lectures and creative workshops.
9. I understand that my participation in this study is voluntary and that I am free to withdraw at any point until 31st Aug 2022. I will not need to give any reason and this will be without consequence to me personally.
10. I would like to receive a summary of the findings of this study.

Your contact details

Name:

Medical Specialism(s):

Email address:

Contact telephone number:

Signature:

Date:

Please return this form to the Study Researcher, Rhian Solomon
By email r.solomon1@arts.ac.uk

Thank you for completing this form

APPENDIX D – DATA COLLECTION TOOLS

APPENDIX D.1. INTERVIEW SCHEDULE – FACILITATED WORKSHOP INTERVIEWEES

Project title - Design Facilitator: The Body as a meeting place and materials as medium for enhancing communication and collaboration

Student researcher - Rhian Solomon

Academic institution – University of the Arts London, London College of Fashion

Workshop Facilitator interview questions

1. Can you describe your practice?

2. What role do materials and/or objects play within your practice?

'I'd like to talk to you specifically about project X - the role of materials and/or objects that you employed and your role as a facilitator in this project.'

2a. Can you describe the materials and/or objects that were used in these activities?

2b. What was the significance of using these materials and/or objects during these activities?

2c. What informed your selection of materials and/or objects for these activities?

2d. What was the overall aim of these activities?

3. Can you describe your role in developing these activities?

4. Can you describe your role in facilitating these activities?

5. Can you explain, how materials and/or objects were used within this project to open dialogues about subjects or experiences related to the human body?

6. Can you explain why materials and/or objects were used within this project to open dialogues about subjects or experiences related to the human body?

7a. Do you feel the select materials and/or objects opened dialogue between participants about subjects or experiences related to the human body? (You can include also yourself as a participant.)
Yes/No.

7b. If yes, between whom? And how?

8. What was the participant's response to the use of materials and/or objects within these activities?

9. Do you feel there are benefits for using materials and/or objects to open dialogues between differing groups when discussing subjects or experiences associated with the human body.

Yes/No.

If yes, what are the benefits in your opinion?

10. Do you feel there are challenges when using materials and/or objects to open dialogues between differing groups when discussing subjects or experiences associated with the human body.

Yes/No

If yes, what are the challenges in your opinion?

End of interview

APPENDIX E – DATA

APPENDIX E.1. FACILITATOR INTERVIEW TRANSCRIPT - TERESA ALMEIDA

START AUDIO

Rhian Solomon: Okay, so this is an interview with Teresa Almeida. It's 23rd April 2018. Thanks so much, Teresa. I really appreciate your time. I really do. I'm going to start with quite a broad question to start off with. I was wondering if you, first of all, could describe your practice to me.

Teresa Almeida: Hmmhmm. So I haven't practised the answers, okay, so it might be a bit... (Laughter) My practice: oh, how would I describe that? So it's design led, all the work that I've been doing the past few years that I'll be talking about. It's design led. It looks into how we can design technologies to improve the quality of life. I guess my practice has focused a lot on women, on women's bodies. Most recently, it's been focusing on women's bodies and the personal intimate care that goes on within the body, and thinking about, speculating about, trying out different digital technologies that include physical interaction and tangible mediums to actually talk about those issues of care that go on within the body that might be a bit sensitive. I'd put my practice under the label of 'Research Through Design' as a methodology, and I've been exploring different kinds of creative methods within that Research Through Design brother umbrella to come up with innovative ways to destigmatise topics that are a little bit of a taboo within care and women presently, if that makes sense. (Laughter)

Rhian Solomon: Yes, absolutely. If you don't mind me asking, what is your background? What have you studied?

Teresa Almeida: Oh, my background? Oh, it's such a mix of different things. I've done Theatre Design years and years ago, so there was my Bachelor's. I worked a little bit in theatre. Then, I went on to work in arts management for a few years. I decided to go back to school and do a Master's in... It's really hard. Do you know ITP? It's a programme at New York University. It's a mix of Art, Design and Technology. Those were the early days of wearable technologies, conductive threads and all that kind of e-textile-related material, so I was very excited at the time.

After that Master's, I worked for a few years. I ended up in Asia and I was teaching this kind of crafting technology, wearables and very experimental-based classes. Then, I decided to do a PhD – that's why I ended up in the UK – in a more computing-related or computer-based department. That's where the focus on technology has come about, I think.

Yes, so more in this human-computer interaction workplace, but doing interaction design, basically, because my focus has always been on the design and the aesthetics of the interactions. So yes, that, in short, would be my background of the past 20 years. (Laughter)

Rhian Solomon: I was going to say it's incredibly broad. Yes. No, it's just really nice to have that background as well to what you do. The next question I was going to ask you was: What role do materials and/or objects play within your practice?

Teresa Almeida: For me, I see all these objects, all the materials that I use as essential for the practice. I definitely see them as catalysts for these discussions, for these conversations around all these sensitive topics. I think they are a way to break the ice, and then to start with, it's a way to actually reach out to these different communities of women that I work with. It facilitates that first approach.

It also facilitates, for example, doing the workshop. It facilitates their conversations around the table – yes, I think coming in with a set of creative materials and the kinds of materials or the kinds of objects that let people in a workshop actually discover different things and do on their own. It definitely makes

it easier to talk about things you wouldn't talk about otherwise. That's how I've been using these different materials and these different accessories, objects or artefacts then.

Rhian Solomon: Okay, so I'd like to talk to you about your PhD project and the role that materials and/or objects that you employed within that project, but also your role as a facilitator in that project. Can you describe the materials and/or objects that were used in these activities? You might want to give a bit of background about the particular project as well beforehand, actually.

Teresa Almeida: Yes, so my PhD work is called 'Designing Technologies for Intimate Care in Women'. What it is about: it all started with thinking about pelvic health in women and how this was somehow something that wasn't really known to most women at different stages of their lives.

It's also something that is not included in the curriculum, at least in the UK, and as far as I know, nowhere else in the world. It could be part of Sex Ed, for example, but no part of Sexual Education in schools includes pelvic health, but which is very important not only in relation to sex but also in relation to things such as body posture and to all kinds of more complicated illnesses and disruptions that come to a woman's body with time, after childbirth, etc., by organs moving from place to place.

It's a very complex system, our body, and areas are easily neglected. I was thinking at the time of how to actually design in a way that could promote preventative care in pelvic health. I focus on women. Of course, men also have these kinds of issues or they have similar types of issues, but I focus on women. I thought, "Okay, so let's find a way that's easy enough, that's not medicalised – find ways to share this information and understand this information so that it can contribute to a healthy..."

Not even a healthier lifestyle, but thinking about the body throughout the life course and how it changes, and start to think about it not only at the stage where you have to go and see a doctor, but actually understanding how the body works and maybe even not ever have to go and see a doctor at the time, focusing on incontinence and looking at urinary incontinence. What is, in teenagers, giggle incontinence? Why does it happen? Is it normal? Isn't it normal?

So all of this is helping you want to tackle it in a way that is not scary because incontinence can be really scary for some women if they don't understand what's going on. Also, it's how to make it accessible in a way that is not medicalised, and it's also fun to learn about. It also makes it easy to come across, as in our bodies are normal, we have all these different bodily fluids, all these different things that happen.

They're all normal, but we need to learn that that's true because, otherwise, any event that happens, any disruption, if we're using this 'body disruption' concept, anything that happens is scary and it's a taboo, so you don't really talk to anyone. You wait way too long before you go and see a doctor, etc.

So it's how to make this a little bit more of a common language, how to make it more... Yes, I like the word 'accessible'. I think it sums up the idea behind coming up with all these different material kits that I created at the time. I explored these toolkits with a wide age range. Sorry, I'm just rambling now. I don't know where to start.

Rhian Solomon: No, no, it's great.

Teresa Almeida: So the first toolkit was an electronic textile toolkit. I'd done that in the past, so it had this little bit of technology. It also had the aesthetics and it had the interactive components that I was interested in exploring in this new toolkit that, potentially, could help advance this kind of discussion.

I had workshops. I first had the workshop with young teenage girls aged 15 to 16. That was really interesting because the toolkit was designed for an awareness of the pelvic floor and the pelvic floor muscles.

I went in assuming that girls at 15 and 16 knew a little bit about their bodies, so they would actually have a basic understanding of where they pee from, where the menstrual period comes from that and all of that because, supposedly, they also learned that in school. I'm not saying at home, but at least in school, they would have learned that.

The surprise at the time was, "That's not true, actually." A lot of these young women had no idea what was going on, at a very basic level, in their intimate body and these different bodily functions. So that was really interesting. It made me take a step back, include a few more materials, and also make the decision to have the workshop with women from different generations.

So I had a workshop with women in their 20s, 30s. I had another one with women all the way up to 40s, 50s. I had another workshop at a women's centre with migrant women. I don't recall their ages, but I would say they were all under 20s, 30s, but from different backgrounds – mostly South Asian. It was really interesting also to see the social, cultural background and how either sex or the understandings of the body might vary – so exploring it from a different context.

Rhian Solomon: Absolutely.

Teresa Almeida: Yes, and the different generations. Some of the women already had children, so they had knowledge of pelvic fitness from that perspective, I guess. In the UK, from what I'm told, at least after giving birth to a child, the woman is told to do the pelvic floor muscle exercises. Not necessarily explained how to do it, but not before at least she hears about it or she learns about it at that moment. I guess then it's all about Google. I'm not sure how that works. There are not that many materials that teach these things.

Now, I've lost my train of thought. Yes, so for this specific toolkit, the materials changed slightly throughout the different workshops. For example, one of the first activities during these workshops was a body-mapping exercise, which basically just meant they were in groups of two and I gave them a pair of underwear - just Y-front underwear. I asked them to think about the reproductive organs and draw the reproductive organs if they could on that piece of underwear, if they had an understanding of where it went.

Maybe some of them were outside the underwear, as one of the girls mentioned, thinking about the position of the different organs in the body. Where do they go? What is it that they can sketch on that piece of fabric? It's just to get them started and also to understand what they know, what they don't know. That's also how you understand in a workshop setting that knowledge is actually quite limited. (Laughter)

Then, the second activity was related to that. It was a new piece of underwear that had a little soft circuit, so the textile already prepared for them. It had a little soft circuit, and there was a screen print of all these different pelvic muscles. It was a flat pattern. They had to assemble it.

When assembled, it would show the female perineum as a whole, but the design would show the muscles - so it's the layer underneath the skin - just to help visualise that what we have there is this bunch of different muscles that link together in some way in the way they connect to each other depending on how you move them. If you do the Kegel exercises, the pelvic floor muscle exercises, those muscles lift and you contract and relax, so it's trying to visualise that in some way.

It's very difficult to explain. It's very hard to visualise. There are different techniques that you can touch on your body, and you can feel the muscles contracting or relaxing. So it was a lot of new knowledge. With the e-textile, I tried to just have a very, very simple kind of... Not even interaction, but it was just like these little lights going up and down to simulate the contraction and relaxation.

After everything was assembled and put together, if it was put together the right way, otherwise, it wouldn't work, this would take an hour of discussion between them. During the image of the female perineum and the right way on the piece of underwear, even that was challenging. I mean, there were only two ways to do it - either upside down or the right way. Even with that, there was some discussion around it. So it's just showing that we don't really think much about our body almost.

Rhian Solomon: So the sensors interacted with the participants' bodies or the sensors interacted with the prints that you constructed? Were they on fabric, on the garments, or are they on paper - the prints?

Teresa Almeida: The sensors: so it was a very simple system. It wasn't reading real time, so there was no way to know in reality whether the person... So the girls actually put the underwear on. For ethical reasons, during the study, I couldn't really ask women to put them on, but the girls asked me if they could put it on, so that was really nice. They were very intrigued, trying it out and thinking, "Oh, I'm doing it now and the lights are going on and off," but someone else was saying, "Oh, I'm not doing anything, but it's still going off." (Laughter)

Rhian Solomon: Brilliant. (Laughter)

Teresa Almeida: Yes, so it wasn't reading anything on their bodies. It was just a simulation. It's almost impossible to actually do that in real time. I mean, there are a few prototypes being developed in order to do that. I don't think there's one yet. For my study, that wasn't the main concern. Even having the simulation was more interesting in this case because I just wanted to promote this kind of discussion and confusion anyway just to see what would come up out of it.

Rhian Solomon: Absolutely.

Teresa Almeida: Yes, so it was all incorporated. It was all textile. It was all incorporated into this piece of underwear. It was this floppy pattern that would be with metallic snaps that would attach to the

underwear, and that's how the circuit would be put together. Then, there was a little soft circuit that would close that bigger circuit – that would make the lights go on and off. Yes, a very rudimentary piece of e-textile, though. (Laughter)

Rhian Solomon: Lots of conversations occurring - unexpected conversations occurring and general conversation occurring as well throughout the session?

Teresa Almeida: Yes. Yes, so just that confusion and then the idea of talking about these different parts of the body, and cutting and assembling and looking at the visuals. Of course, the visuals... They have a vagina or they have an anus and all those different recognisable parts that make people really embarrassed, and at the same also laugh and tell stories. So that was quite interesting, yes.

Rhian Solomon: So that leads quite nicely on to the next question, which was: What was the significance of using these materials and/or objects during the activity? You talked about, obviously, using garments and electrical components as well, so what was the significance of using...? Why garments, or why underwear?

Teresa Almeida: Yes, I'm still reflecting on that now, trying to start new work, and thinking about it. Well, I think from that one workshop and also from the work I did afterwards, this idea of embodied knowledge is quite appealing to me. I like the idea of designing for embodied knowledge – the difference between designing an application on a mobile phone or designing a mobile application that works only if you look at your body, which is the other study I did.

I think that somehow, as awkward as it might sound or feel while doing it, just the act of physically having to look at some body part or looking back at your body other than just looking at a screen on your phone, that already prints something on you. I think it's more memorable. I think, if nothing else, it makes you ask more questions and really look on the body, not just on something you have when you're at home.

I've lost my train of thought again. What was I supposed to say? Yes, and the materials... If we're talking about the body and thinking about clothing, this idea of second skin, then I also really like, and if designing to learn about the body, then let's do something that expands on that. Also thinking about how technology expands the body, then the very first thing that would come to my mind would be this layer of textile, this layer of fabric, that layer of protection that we use on a daily basis.

They're also technologies, and it's a technology that we put on on a daily basis without even thinking about it. So this idea of everyday life, everyday routines, which is the routine of putting on underwear, putting on a shirt, putting on whatever accessory, using whatever accessory it is, I find that interesting as material to work with. Yes, I think it all originates from that.

Rhian Solomon: If you don't mind me asking, what is it about the everydayness of clothing that you...? This is a slight deviation, but, yes, I...

Teresa Almeida: Yes, well, I guess I was thinking - and I still think about - this idea of being overwhelmed with technology and just having more things that we don't really need. It's also thinking about these new learnings, so learning something new by using something that you already have or that you're already used to - for example, putting on a piece of underwear, because it's already embodied, the putting on clothing. So why not use that as a way to promote those other routines?

It's also thinking about how these different types of clothing could actually integrate. I don't want to go in that direction, but it's how you monitor different aspects of your health instead of having more trash, like you can already use what you have in a smarter way. You don't use any more...

I don't know. I'm a little bit concerned about putting things out in the world that are really that needed. They're just fashionable for a little while, but then not needed. So I was thinking about ways of optimising this everydayness and how to use that to actually improve these routines of care, I guess. Something like that, if that makes sense.

Rhian Solomon: Yes, absolutely. Sorry, I know that I am putting you on the spot a little bit because it is leading to other questions.

Teresa Almeida: Oh no, it's fine.

Rhian Solomon: So there are a couple that are deviating.

Teresa Almeida: It's okay.

Rhian Solomon: I think that's brought us on to the next question, which is: What informed your selection of materials and/or objects for these activities? You started to talk about that. Is there anything further you wanted to add when you were considering perhaps the materials that you were screen-printing on to or the clothing that you were using?

Teresa Almeida: Well, I guess there were a lot of different variables that helped decide that. Well, I want it all to be, first of all, comfortable. So for example, in the other study, the second study, I had these other materials that different women used individually. They had to take the materials and try these on at home. I custom-made the underwear for each one of them. I mean, there are differences. I wanted them to be comfortable. Some women feel comfortable in boys' shorts and others prefer a bikini or... I can't remember the names of the different underwear I used.

I had them choose what they preferred, what they liked. Also, in terms of colour, if there was anything that they preferred... I think all these different details are actually quite important in doing a study as such. So it's not just following the very standard...

Yes, customising, I think, was important. It would be for this kind of study. In terms of the tactile aspect of it and thinking about the screen print, for example, it was just a very generic piece of fabric because of the different tools I had available to me and also having to make it work other than just thinking purely from the aesthetics point of view.

So there were a lot of constraints, of course, but if I do the project or if I work on it now, I would be more careful about the selection of materials. I would want it to be more perfect than it was. I guess, at the time, customisation, I think, was one of the main concerns, and using just basic materials such as cotton, even though maybe someone else preferred silk. For the purpose of the study, it was all basic materials, whereas, if it was a product, I guess the selection and the refinement could see a lot of improvement.

Rhian Solomon: When you said 'customisation', you talked about the style, the colour and the fit as well – is that right?

Teresa Almeida: Yes.

Rhian Solomon: Was it that you had a different-sized women so you were making different sizes of underwear, effectively?

Teresa Almeida: Yes, different sizes, different fits, different colours, different prints. They were all screen printed. I hand-printed all of them. Again, for the study and for it to work, it had certain constraints on the print. I wouldn't say the print was the print I idealised, but I had to make it work, so... (Laughter)

Rhian Solomon: So the print was at different scales, was it, depending on the different participant size of everyone or...?

Teresa Almeida: Yes, so the print was on the crotch of the underwear, so it filled the entire crotch. Oh, what do you call that? So that block – the pattern? No, not the block pattern.

Rhian Solomon: Yes.

Teresa Almeida: Yes, so that area would be filled with a background colour. Then, it had different... It was a combination of three colours. It had to have a very specific shape in the middle because the camera on the mobile phone... That's what it would recognise. So that's how it worked. I had a mobile phone that acted like a mirror almost and the woman had to use it as a mirror looking at her own crotch. There was the link between the body and the digital.

So in this case, the print had a very basic shape that had to be recognised by the mobile phone. Ideally, I would like to work on that pattern a lot more. Yes, at a later date, it would be a different print. Yes, so the underwear was screen-printed on the crotch area and it had these different patterns and background colours – different patterns to stimulate a little bit of the muscle structure. Then, it needed this other figure, which was the figure or the shape that the camera phone would recognise.

All of this had to be done with different colours, and the darker one had to be the one used by the shape the mobile phone would recognise. So there were these kinds of constraints. The pattern had to respect the technology in that way, because, otherwise, it wouldn't work. (Laughter)

Rhian Solomon: Yes, absolutely. Okay, I'm just jotting this down. Okay, so what was the overall aim of these workshops? In fact, before that question, could I just clarify that when the women were putting their own underwear on and using their camera, they were doing that at home? Was that the second stage?

Teresa Almeida: Yes.

Rhian Solomon: That was because of their fits or...? What was your reason for them doing it at home?

Teresa Almeida: It wasn't even ethics. I think it was just a decision that it was a very intimate kind of act, just as you grab your mirror and you look at yourself kind of thing, but in a more augmented way. I think it was also a decision that this would be a material skin that a woman would take with her and would keep for... I think, at the time, I asked them to keep it for a week - just try it out whenever possible and then we would convene and just talk about it.

Yes, I think, contrary to the previous one and having women in a workshop setting, this one was more of an individual kind of experiment.

Rhian Solomon: Then, you regrouped with the women and discussed their experience of that interaction? Is that what you did?

Teresa Almeida: Yes. Yes, exactly - also, individually, so no one knows who the other participants are, except me. I would meet them individually in a place of convenience and just go through the experience. I also had a few questions. Yes, that's how that second study happened. So I had 14 women, individual women, doing that study. I later on did another study with couples - very heteronormative couples. I had seven couples.

At the time, we were just intrigued at how any of this could work if used within this kind of partnership - intimate relationships. Yes, so I also did a study on that and I also included on the PhD. It's on the thesis. It's not published anywhere else. I don't know what to think about it yet. (Laughter)

Rhian Solomon: Yes. No, that's okay. I've put you on the spot again. Sorry. If you could just give an overview of what the overall aim of these activities were...?

Teresa Almeida: Well, overall, the main interest was in creating these new designs that let women have more awareness of their intimate bodies, doing it also in some fun... Well, I don't know if I want to use the word 'fun', but in a very playful way - in a way that is relaxed. I think the first activity, the one with the screen print, showed that that was possible. There were different things that could be incorporated into a design that could help create the awareness in a playful way while destigmatising the topic.

The second one: well, on the second one, the one that combines the underwear and the mobile app, I think that's what I was trying to do. It was a very ambiguous design for research purposes. The app, for example: in the way the app was designed, it didn't look to give any answers to the women trying it out. It tried to have more of an open-ended conversation, so there was a lot of ambiguity in the way it was designed - again, for research purposes.

If we're designing it for more of a product, it would have to be thought through in a different way. For research purposes... I've lost my train of thought again. Yes, I'm just wanting to say that this idea of the ambiguity in the design can be very helpful, I think, when doing research because you're not really giving all the answers, but you're actually asking people to think about it, talk about it and ask questions about it. That, of course, can help in implementing a follow-up, another inclusion of that design. Just to say, now, I've really lost it. (Laughter)

Rhian Solomon: That's okay. It was the aim of these activities.

Teresa Almeida: Yes, so the first one was trying to explore the design requirements - all being required to design this new piece of technology that would support women in learning about their intimate bodies in a way that can support intimate care. So it's how to improve body knowledge and how that body knowledge could actually lead to better self-care.

That led to this second case study, which I think tried to combine all of that – so thinking about different technologies that are already there on an everyday basis. Everyone has a mobile phone, so why not take that? Everyone wears underwear. So just thinking of the general project, everyone wears underwear and everyone has a smartphone. What is it that we can do with that?

It's just use those technologies in a way that they can create some kind of awareness on all these different topics and contribute to this idea of preventive care or self-care – the different qualities that come with it. I was talking about the customisation of the underwear and whatnot, the cotton, so this idea of touch, which is a quality of intimate care, as I try to frame it in my work. The way all these different textiles touch your body and how you touch them: it's all a quality that supports here, because of the way you feel comfortable with what goes on your body, what touches your body, etc. I think this overall project was very much focused on this idea of self-knowledge and gaining knowledge in a way that promotes intimate care from these different perspectives. So yes, I think that is supporting... Yes. (Laughter)

Rhian Solomon: No, that's great. The next question is: Can you describe your role in developing these activities?

Teresa Almeida: You mean what was it that I did?

Rhian Solomon: You've alluded to this partly already because you're obviously developing those activities as part of your PhD research. You had, obviously, the activities that you used during the workshops, but the development of these activities and your... Yes, I mean, it might be that it's part of your background and your experience that has informed that. How did you come to develop these activities?

Teresa Almeida: Well, basically, it's very much informed by background. All the different workshops I've done with e-textiles, for example: I've done so many around the world with different people, mostly girls and women. Also, the previous design/artwork I've done within this realm of wearables and wearable technology. They were very conceptual and also very critical, so I think that also influenced the most recent work I've done.

Definitely, all the feminist readings I've been doing throughout the years – I think that also has a huge influence on this piece of work. So I think without all that acquired knowledge and all these different interests... Of course, this is all very dear to me. It's subject matters that I'm quite passionate about, so having the opportunity to work on them just brought all of these different experiences and my background together. It just happened, I guess. (Laughter)

Rhian Solomon: As it does. (Laughter)

Teresa Almeida: Yes, I would say, definitely, it's a reflection of my work the past few years. Yes, it didn't just fall from the sky, for sure. (Laughter)

Rhian Solomon: Okay, thank you. The next question is: Can you describe your role in facilitating these activities? So you've talked about the materials, but your role within these workshops...

Teresa Almeida: Yes. So definitely, I was a person... Oh, now I've missed the word. Yes, facilitating the workshop, of course. I had it organised through activities, and within these activities, the participants had absolute freedom to talk between them and ask me questions. Also, one of the very important things was that I'd come into these workshops and I had to make it very clear that I wasn't a medical expert, because there might have been that expectation.

I'd come in as a designer, as a researcher, and not as a medical expert, so if they had any questions related to the pelvic health or related to any other reproductive, sexual health issues, of course, I would have to advise them to go and see a professional – a medic. That was something that I had to make clear because, at some point, I started having some questions that, of course, I had no answers to.

I guess some women might have seen the workshop as an opportunity without making an appointment. I don't have that expertise, so I had to make it clear that it was an experiment of sorts and we were just trying out these new designs and these new ways of doing and thinking, and seeing if they

could help me in understanding whether they worked or not so that other women could have access to them and also learn with and through them.

I think the series of workshops required a little bit of facilitation for sure because a topic that proved to be quite foreign, like pelvic floor, pelvic exercises and pelvic health, required some imagery. It required me to explain some of the imagery besides the toolkits.

I don't know how to describe it. For example, in the first workshop with the teenage girls, I had the teacher with me. So for ethics, the gatekeeper had to be there, which proved really useful because, of course, the teacher had a relationship with these girls that I didn't coming in. It was the second time they'd seen me because I'd been there before to ask if they would like to participate etc. In total, they saw me three times.

Of course, a lot of questions would come up. It was a lot easier for the teacher to answer them than it would have been if I was on my own, I think, because of the limitation that comes with not knowing the group of people. It's quite interesting, actually, to think about that when you come in for a couple of hours' workshop and you try to deliver and get all this feedback in a couple of hours. The relationship you establish is very different from someone who has a session with you on a weekly basis or over many months.

So in the beginning, the toolkit, for example... I still think that the toolkit as such would be a nice piece of material for a teacher to have and deliver in the classroom. It would be interesting to see how, if there was a case, if there was a teacher facilitating this conversation, how different it would be with me as a stranger, a foreigner or foreign to their ecosystem, how it would have affected the way they talk about things and the way they disclose things. Yes, it would probably be a bit different, but, in terms of the facilitation, I don't know what else to add to that.

I think it had to be quite structured because of ethics. The first thing, when putting ethics, you already have to have it really well structured. Then, on location, things change, depending on... (Laughter) You, basically, have to accommodate different audiences because the way they respond is also quite different.

Out of the four groups, the four workshops I had, one of them was very difficult I think for me because I didn't have much participation from the participants. That meant that my facilitating of the workshop was very demanding. I had to be on all the time, and I also had to explain maybe too much because I was expecting the participants to do, discover and talk between them, but that wasn't happening. So I had to go ahead and explain so that then they would actually feel like they should be doing and taking...

Rhian Solomon: Why that particular workshop, do you think?

Teresa Almeida: So now, I think that that was the only group where the women didn't know each other previously. Yes, for example, the girls were used to being in class together. They were classmates. In the women's centre, it's all women from different parts of the world, but they also come in together and have workshops frequently in the women's centre and they socialise.

In the other group, which was 20s and 30s, more or less, they all knew each other – maybe not so much on a personal level, but they were quite familiar with each other and knew each other's work. They'd seen each other, etc. It was the older one, the 40s, 50s, where I think they didn't really know each other. Maybe they were just more aware of the different topics and they didn't participate as much for different reasons. I didn't ask them afterwards. I can only speculate, of course, but I think there was a little bit more embarrassment.

Rhian Solomon: Did you have people that were speaking English as a second language or other language?

Teresa Almeida: Yes, I did. I don't think there was a problem, though. I don't see it in any of these groups as a problem. Even in the women's centre where, yes, English for some of them was even a third language, I think it was actually quite okay. In the group where they were not participating as much, actually, I think they were all speaking English as a first language, so definitely not a problem. Yes.

Rhian Solomon: Okay, so the next question is: Can you explain how the materials or objects were used within the project to open dialogues about subjects or experiences related to the human body?

Teresa Almeida: Yes, so all the materials were all about the human body, for sure. So they were designed on purpose and very specifically about different bodily parts. All the materials were very visual,

so there was no problem anyone looking at it and not understanding what some of those parts were. The problem comes when some people realise what the parts are and how that sometimes prevents people from even looking at it. (Laughter)

This happened more in conferences than in the workshops, actually. In the workshops, I think there was a genuine curiosity about participants to learn more. Yes, so all the materials, the toolkit were clearly... I mean, the screen print and the design that was also part of the toolkit that showed how to assemble the different parts are very graphic.

On the second project, the underwear and the mobile app, which shows a snow-white mirror on the first screen, that looks very innocent at first. You can't really tell what's going on, even though asking someone to put on a piece of underwear and use a mobile phone is already new. (Laughter)

Then, when that first interaction happens, you actually have this augmented female perineum, so again a very, very big graphic, and you're immediately invited to touch. So yes, it's all very direct in the sense that there are intimate parts of the body, which was what the project was all about.

Rhian Solomon: Can you explain why materials and/or objects were used within the project to open dialogues about subjects or experiences related to the human body? You've alluded to this already in other questions – number six.

Teresa Almeida: Oh, yes – how they were used?

Rhian Solomon: And why they were used.

Teresa Almeida: Why? Yes. Yes, so basically, using materials as catalysts for igniting these discussions... I think it goes back to this idea that when you're actually making or when you're doing something, you're not just looking at someone talking to you... It's not a lecture kind of environment. You're actually multitasking. Like with the pattern, you're cutting at the same time as you're talking to someone next to you. It feels from what I observed and also from this experience that it actually makes it a lot easier to talk about things you wouldn't talk about otherwise.

I think that was one of the objectives, actually – to create this kind of environment that lets you learn these different things through making things. Instead of complicating them, you just make them easier because you're doing all these different things at the same time, and without noticing, you're already talking with someone you'd probably not talk about these issues with. It just makes things feel a little bit more natural.

Yes, I still feel that way. I think it's a good way to bring in these different topics to someone who might not be used to talking about these topics, and bring it to them in a way that is just very clear. It's simple in its approach. Yes, it's the opposite of complicating with jargon and things like that. You just make it accessible, yes.

Rhian Solomon: So there's an element of translation in the sense that you've obviously had to have a knowledge of female anatomy to then translate that information into an accessible form to facilitate these discussions and interactions?

Teresa Almeida: Yes, and one of the other parts of this research that I didn't mention was that I did this ethnographic piece of work – women's health, physiotherapy. I was just observing how different women were taking care within this clinic kind of situation and how they were explained how to do the pelvic floor muscle exercises, and how they were shown anatomical models to see what the pelvic floor muscles were and how they were affecting their internal health and whatnot.

Something that was striking at the time was that you could clearly see that women were confused when looking at these anatomical models. I was confused. I had no idea what I was looking at. It took me a while to understand all of it. That also made me understand that, well, maybe we can approach this in a different way. Maybe there are different ways we can represent the human body in ways that are more, again, accessible to all these different women – all different people.

Then, I was also thinking about ways that I could possibly contribute to doing that. I'm not that knowledgeable. I mean, I learnt as I went. I admit that, at the beginning of the project, there were a lot of things I didn't know, so it's been a huge learning curve in a very good way.

Now that I'm planning to redo some part of the work, I know some mistakes have been made. Now, I look at the screens, for example, the digital interface, and I see some of the information I put in there. I can immediately spot the mistakes. (Laughter)

It's interesting, but also taking it from my experience, I think it's important to learn again... It's going back to the basics. You can't really complicate things. You can't really know the complexity of the body without understanding the basics of the body. So maybe starting from there is a way to go. I imagine, thinking about the confused looks I saw in this clinic, for example, maybe that's the way to go, really. You don't have to even explain where the bladder is. Well, in a cross-section of the body, maybe...

Yes, we have to find different ways to show where the bladder is and how that might be connected to the pelvic floor muscles in a way that is less abstract, in a way that people can actually feel on their bodies. I don't have an answer to it. I've just been speculating and exploring different ways that I can possibly do it. Yes, I lost track again, sorry. (Laughter)

Rhian Solomon: No, that's fine. I'm wondering whether – obviously, you're a woman and you're working with women - what things might be like if you were running a workshop where you were developing models to work with groups of boys, and how your gender would... I don't know if you've written about this, but I'm just trying to imagine that kind of context.

Teresa Almeida: Yes, I haven't done anything about it. I think it would be a very important piece of work to be done. I'm not sure I would be able to do it or if I would like to do it. I think all the work I've done so far comes from this relatable kind of bodily experience. I'm not sure I would be the best person to convey this kind of experience to boys or, in this case, someone who has a different anatomy, because then comes the gender issue thing.

It's very anatomy specific, which, from my health perspective, is quite important because it's the body parts that have to be treated independently of gender. I've also been thinking a lot about that and debating about that. Again, I still don't have answers, but thinking about designing for pelvic floor muscle exercises in men would be a really, really interesting and a really important piece of work to be done, because there's nothing about it.

When I present this work in different venues, I always have men asking different questions, and they actually have no clue. Very few know that they have these pelvic floor muscles let alone that it all has to do with their own sexual performance. So that would be a good approach to get boys and men interested in their own intimate health, just combining this with their own performance.

Yes, I don't think I would be the person to do it, though – I think because I think about the work that I do from this... Yes, how it relates to my own experiences. It all comes a little bit from my own experiences, or I'm interested in exploring it further, thinking about the experiences that I might have.

Rhian Solomon: Do you feel the select materials open dialogue between participants about subjects or experiences related to the human body?

Teresa Almeida: Yes, I think so. Well, with the first one, working with the textile-based materials, definitely, because I think, in general, people immediately see it as something that goes on the body. So I think automatically it creates this idea of a second layer of skin. I don't talk about it in a way, but it is a second layer, so by extension and thinking about the layer of pelvic floor muscles and the layer of skin, so thinking about all these different layers, I think it helps.

Working, for example, with the mobile app and thinking about it as a mirror, I think that also helped, and also going back to this idea of having the design being so ambiguous – for example, in the part that the app invites to touch so that there is some kind of information or there's some kind of feedback. That invitation to touch is also very ambiguous.

Of course, the woman is expected to touch on the screen because that's the only way the interaction is going to progress. At the same time, she could be touching on her own body, so understanding and feeling what goes on on the body. One example is that there's an animation of the pelvic floor contraction on the phone when touching, and then when touching the area of the screen that we know is the perineum.

That's one of the techniques to understand on the body – whether the contraction is happening, the relaxation is happening. So the woman can touch on the screen, but can also touch on her body to understand better whether it's happening or not.

This was a piece of digital material, right? It was all on the screen, but I think it somehow creates this relation or invites this kind of embodied experience, because it was designed to be that way. Not just a let alone thing that happens on the screen, but actually an invitation to come back to the body as the main material, actually, and just try it out.

Definitely, I think the material we choose to work with are extremely important, depending on what you're trying to achieve, of course. Talking about the body: definitely. Anything that goes on and

within is very important, and because I was exploring these qualities of intimate care that involved, well, everything from knowledge, to touch, to esteem, to reliance – how you rely on other people to manipulate your body, yes, it's so important. I'm working on this idea of mindful materials now. I'm not sure where I'm going with it, but... (Laughter)

Rhian Solomon: Is that something you can talk about or is it something that's a new project?

Teresa Almeida: It's a new project and it's still in its very early stages. I've been doing a lot of reading and I'm trying to come up with a vocabulary to formulate it a little bit better by thinking about epistemic practices and epistemic objects. Yes, and thinking about mindfulness in a different way, but, yes, I'm thinking about this quality of esteem that looks at touch from the series of qualities of intimate care that I've put forward in the thesis. I'm trying to go back to that.

I think now I want to look at all these different medical tools and all these different devices that go on the body when we talk about care and how they touch the body, how it feels, how different people have to use it and how they touch it. I'm not yet sure what I'm doing with it. Yes, it's quite a blur. I'm just reading it right now.

Rhian Solomon: Well, there are just so many directions with your work, though. It's just – I don't know – deciding which one to do first, more so.

Teresa Almeida: I know. Yes, I have to be strategic. (Laughter)

Rhian Solomon: Absolutely. (Laughter) So do you think that the materials that you used opened dialogue between the people in the session? Also, you can include yourself as a participant within the session.

Teresa Almeida: Yes, definitely. Yes, I think in all of the sessions, some were, of course, more successful than others, I guess, but that's the beauty of research – that you have that entire material to analyse.

Rhian Solomon: What was the participants' response to your use of materials within your activities?

Teresa Almeida: Oh, so I remember with the screen print, they actually really enjoyed it. I think they actually liked the touch of it. This was a calico-based screen print, so it wasn't a soft... I think they really enjoyed it, and they also really enjoyed the cutting and the assembling. It's such an easy and straightforward activity that I think made people happy.

It also gives them time to think through things. These were some of the comments, actually, that they had. It was just the entire thing, like working with those materials gave them time to reflect. Touching those materials and playing with them: they also appreciated that.

The use of underwear: for some reason, it's awkward, so 'awkward' was the word that was more recurrent in all my interviews, which is great because then you can also speculate a little bit about what makes something awkward. One of them mentioned that even when you go and buy underwear, it's almost that you go on a secret mission. You don't want to see anyone you know when you're buying underwear. Why is that? (Laughter)

I think some of the materials, like the underwear, make people a bit self-conscious, but then again it served the purpose of the research. It is an everyday accessory, so it wasn't just something that I invented out of the blue. It was this idea of using something that is already existing, that you have in your drawer. It's just when you have to talk about it and expose it that makes it a little bit more different.

Rhian Solomon: Do you think that there are benefits for using materials to open dialogues between different groups when you're discussing subjects or experiences associated with the human body?

Teresa Almeida: Benefits of materials?

Rhian Solomon: Yes.

Teresa Almeida: Yes, I would think so. Definitely. I mean, let me see about it. Well, again, I think it's also because of my background. I find it a lot easier, myself, to actually have something tangible or something physical that I can use when communicating, when talking with someone else. To me, it helps

me focus. I think it's also a way to unpack all kinds of different things, because it's a starting point,. Then, from that starting point, we can go in so many different directions and it's very open-ended.

I think, just thinking about my practice, it's all been based on using materials or using some kind of artefact to ignite these kinds of conversations. I think it makes it a lot more interesting, actually, because I think it also gives out the other person's ideas or the opportunity to share ideas that otherwise they wouldn't. Yes.

Rhian Solomon: So there's something about making people feel comfortable as well as giving them time and space to reflect?

Teresa Almeida: Yes. Yes, it creates an environment in which you slow down a little bit and you're actually thinking, especially talking about the body and your body. You're given a set of activities or a set of materials and a couple of hours to work with it. Somehow, it slows down your time in a way that you're already doing some kind of self-care. Yes, I think so. Definitely, especially if you're in a workshop situation.

It's not like you're being asked questions. You're actually coming up with those questions yourself while using whatever is put in front of you to think through. You're already thinking about your own body and your own health, so yes, it's already a way of doing some kind of self-care, this sort of workshop. Yes.

Rhian Solomon: Treating yourself and your body?

Teresa Almeida: Yes, exactly.

Rhian Solomon: Do you think that there are challenges when you're using materials or objects to open dialogues between different groups of people, when you're discussing subjects associated with the human body?

Teresa Almeida: There can be. I think that also depends on how sensitive the topic of the body is and also on individual experiences of the participants. When talking about health, it depends on what kinds of experiences someone at an individual level might have had. So that can bring about a lot of emotions, I guess. I haven't encountered any major issues doing my workshops or interviews, but I can see how easily that can happen.

So yes, there is a little bit of a line there, I guess. I'm not sure that's based on the materials, though. I think it's more based on the individual experience. The materials are not showing anything that should be censored, but it should be more euphemistic. I think it's very subjective when it comes to people's experiences. Yes, maybe some of those materials might be okay with someone and might put someone else with a bit... Yes, I'm not sure how to express it better.

Rhian Solomon: No, that's...

Teresa Almeida: Well, you're working with very sensitive topics, so you've probably encountered levels of acceptance in relation to the body, in relation to illnesses and...

Rhian Solomon: Okay. Thank you.

END AUDIO

APPENDIX E.2. RHIAN SOLOMON – REFLECTION ON PRACTICE

APPENDIX E.2.1. SOURCE MATERIAL



APPENDIX E.2. 2. WRITTEN REFLECTION

Rhian Solomon - December 2024

NIPPLE RECONSTRUCTION – WORKSHOP DESCRIPTION

In 2015, as part of an Artist Residency position at Morriston Hospital, Swansea, I developed a set of creative, facilitated workshops to engage patients and clinicians from the breast reconstruction clinic. The following written reflection focuses on one of these workshops, held in February (2015), in which a group of patients learned surgical cut, construct and suturing techniques for nipple reconstruction surgery.

The workshop took place at Singleton Hospital, Port Talbot, in one of the hospital seminar rooms. I had been advised by the Arts in Health Co-ordinator for the Trust to host the session at a hospital site because it involved working with patients of the clinic. We also ran the workshop outside of regular working hours and clinic times - to connect with as many patients as possible and to recruit a willing member of the surgical staff to lead the session. The session took place in a seminar room which was used by clinicians and hospital staff for non-clinical activities.

The workshop was about learning surgical cut and construct techniques in cloth - specifically a C-V Flap nipple reconstruction technique. I was pre-empting a lot of questions about this from the patients and it was important for me that factual, surgical information could be shared with the women and so the technical demonstrations of the workshop were led by a surgeon. My role was to develop the workshop activities by researching materials and selecting surgical methods to explore, programming the session and selecting the venue, as well as evolving promotional content and recruiting participants. The surgeon running technical demonstrations during the session, Jon Cubitt, was a registrar with experience in delivering surgical training for clinicians within the department. I had tried to recruit a female surgeon to lead the session but I had been unable to. There were significantly fewer women in the surgical team.

The workshop took place 6 months into the residency. In these preceding 6 months I had seen a number of surgeries in theatre, visited the prosthetic departments to learn about different technical processes, as well as the fitting of prostheses (breasts and nipples). I had also attended nipple tattooing clinics and spent time in the medical imaging department which had advanced scanning technologies and a photographic studio used to document stages of treatment for patients. A large part of my time on the residency, however, was spent in clinic – mostly during pre-operative consultations around treatment options available to patients and in post operative discussions about surgical outcomes, further treatment and recovery.

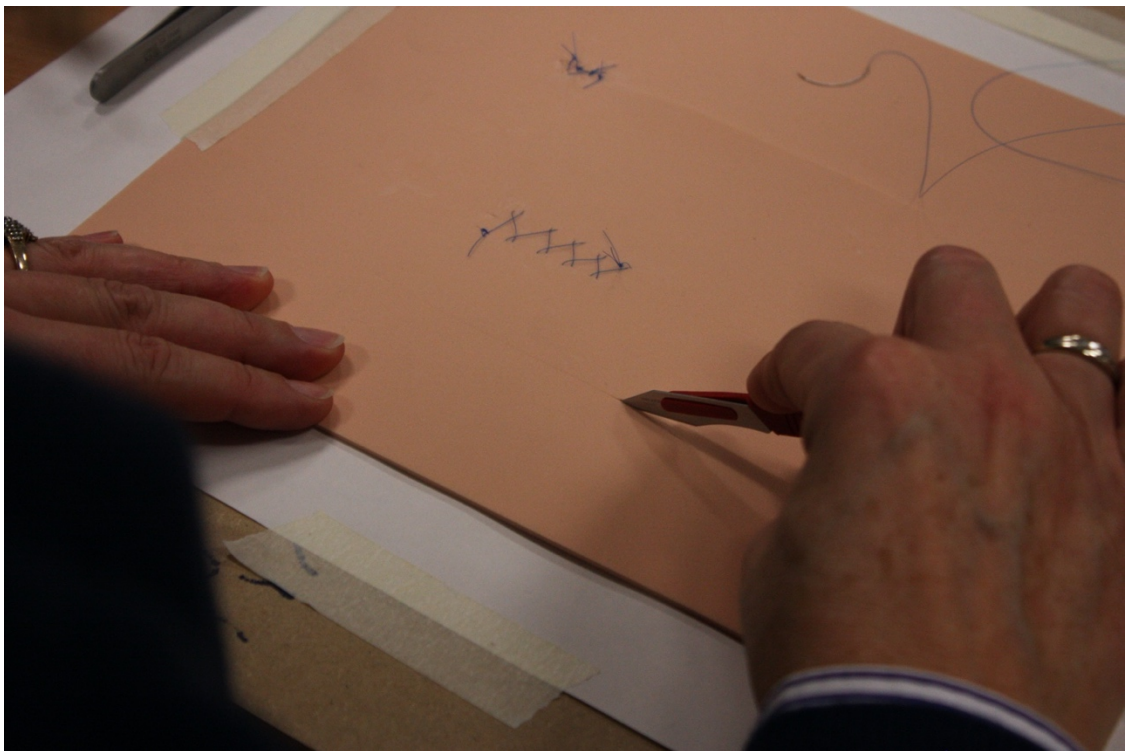
With the nipple reconstruction workshop, I aimed to create a relaxed environment for patients and clinicians to come together to discuss surgeries. I wanted the session to be informative to female patients around surgical procedures that were available to them. The surgeon and I decided that a workshop in nipple reconstruction would allow for a more simple surgical technique to be explored. This was a procedure that was practiced when women, generally, were quite far through the treatment pathway, was considered less complex and was elective as opposed to curative.

The planning of the nipple reconstruction workshop required some thought around the selection of materials. I spent a bit of time trying to locate the correct material for the session. I was exploring different types of neoprene with varying thicknesses and bonded layers. However, the surgeon recommended that we search for materials in the department. The material had to have *flesh like* qualities; with a structure, to support itself, once constructed; a particular thickness that also didn't fray; and that consisted of differing layers. In the end, we used surgical dressings that held these qualities, which were abundant in the department and that the surgeon had had experience of using both in surgical practice but also surgical training. The material came in sheet form. He tested the nipple reconstruction technique on it, ahead of the workshop, and it did what we needed it to do. The women attending all had different reasons for being there. Some were thinking about having a nipple reconstruction and were curious about what it entailed, to learn about surgical techniques, to understand how nipples were made. Some wanted to meet with the surgeon and to connect with other women who were on the reconstruction journey.

The workshop ran with everyone seated around one table. The session began with a brief personal introduction from each participant within the group, including the surgeon, to break the ice. The women didn't know each other. However some did know the surgeon, as he worked in the clinic that they had been treated in. One of the women, coincidentally, had also been treated by him. The aim of the first activity was to support the women to learn general surgical stitch techniques – to get used to using the tools - before attempting the nipple reconstruction technique. The surgeon demonstrated two different suturing techniques. The first, a simple interrupted suture method. The second a herringbone stitch. The surgeon showed the women how to handle the differing surgical tools before showing the stitch techniques.

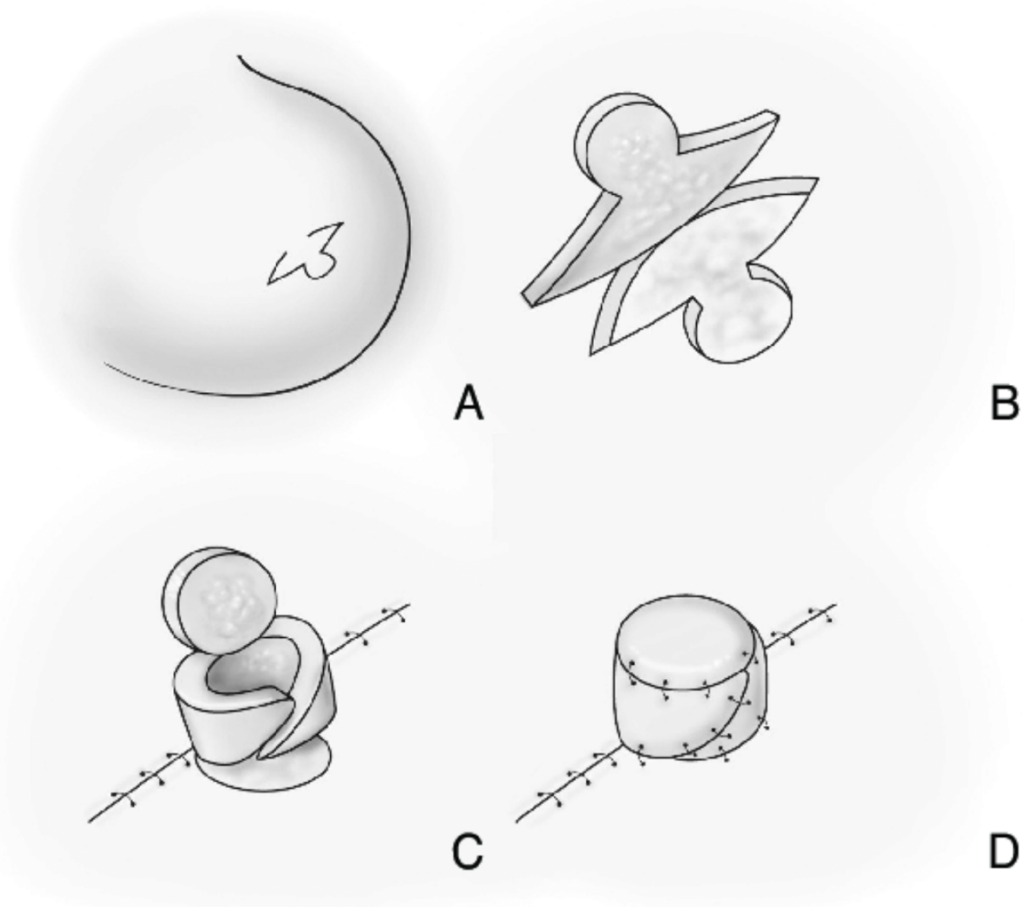
The women followed. Each had a piece of fabric which was taped to the table with a protective cutting mat underneath. Taping the fabric made sure that the fabric was under tension and was kept in place, to help the patients as they cut and stitched the cloth. The women were given their suturing tools – which included non-absorbable, nylon monofilament surgical sutures, scalpels to make an incision in the material, a suture needle holder, stitch scissors for cutting each suture (once complete) and forceps for moving the cloth. The surgeon had also brought along sharps boxes to make sure that surgical needles were disposed of safely.

The women each made 2 short incisions in their material using their scalpel and then applied each surgical stitch to close each incision. The focus was on creating the right tension, and getting the right spacing of stitches. The women asked the surgeon about the technique itself, considering things like recovery time, nipple erectness and tattooing. However, some of their questions focused on the wider surgical journey. The women also asked questions of each other.



Nipple Reconstruction workshop at Singleton Hospital, Port Talbot. Designed by Rhian Solomon and led by Plastic Surgeon, Jon Cubitt (2015). (Above) Surgeon demonstrating suturing techniques. (Below) Detail of patient working. Photographs by Prue Thimbleby.

The next stage of the workshop involved the surgeon demonstrating the C-V Flap nipple reconstruction technique. He drew the outline of the skin flap, at scale, onto the material using a pen, and with a scalpel, followed this drawing to cut the flap. He then lifted and constructed the flap into a nipple shape and tacked these in place, to hold the shape, before stitching all of the incisions.



Lee, D. & Lew, D. H. (2011) Stages of a C-V Flap Nipple Reconstruction. In: Nipple Areolar reconstruction: systematic approach. Available at: https://www.researchgate.net/publication/272414526_Nipple-areolar_complex_reconstruction_Systematic_approach. (Accessed: June 2018).



Nipple *outcomes* – cut and sutured by patient participants (2015). Photograph by Prue Thimbleby.

When it was the women's turn to try this technique they found it difficult when using the surgical tools. However, by the end of the workshop everyone had sampled surgical suturing more generally and had also successfully cut, constructed and sutured a nipple in cloth. They had also had the opportunity across the 2 hour session to discuss surgical procedures with a surgeon from the breast reconstruction department. At the end of session, refreshments were provided, including tea, coffee, biscuits as some people had come straight from work.

NIPPLE RECONSTRUCTION – WORKSHOP REFLECTION

I feel that the venue for the workshop could have been improved. Being in a hospital wing after hours, can be a bit eerie, as there's very few staff in the department. The patients taking part in the workshop also weren't very familiar with the space as they hadn't been treated in this hospital and needed guiding to the allocated room, so it created some practical challenges of way-finding. The hospital had been very accommodating as an employer, in how I worked in the department, however, there were a few limitations on how I could work with patients. It wasn't recommended to work with patients off site. Having a staff contract was useful, though, as I could book

rooms across the hospital sites for different activities. So, in some ways, I feel like there was a freedom in being employed by the hospital, but at the same time, this came with certain limitations. In hindsight, I think this is why I spent the latter part of the residency running activities out of the Maggie's cancer centre that was based at Singleton Hospital - a very different type of space for patients to just *be*. I think that it's probably worth spending some time exploring spaces available for any future residencies or workshops that I do, especially if they are on hospital grounds. There were definitely a range to draw on at Morrision and Singleton hospitals but this just needs a bit more time and consideration.

Also, thinking about the workshop space itself a bit more, I think that the space that we used was quite clinical due to the nature of its use and the lighting within it. This may have been familiar, for the surgeon, perhaps helping him to maintain a professional role to a degree. The patients, however, were unfamiliar with the space and the department. However, I think this could also have had its benefits in affording some geographical or emotional distance from their surgical treatment, in that it wasn't the space in which they had had their surgeries or had pre/post operative consultations. It was quite an alien space for the patients, though, as it was not allocated for patient-facing activities. I think in the future, if there was time, I would consider the relationship that all workshop participants have with the space in which facilitated activities are being held. What is the conventional use of the space and how do workshop participants relate to it in context?

Whilst the space was a bit odd, I feel that changing its layout helped to make a more intimate setting, with everyone sat around the same table. The different ratios of patients to clinicians was also interesting - The consultations that I'd sat in on in clinic usually had 1 patient, sometimes with a family member/friend, and 2-3 medical staff including the consultant surgeon, a registrar and nurse. I think that changing the space and numbers, seemed to support less formal conversations in contrast to clinical consultations. The surgeon was still leading the session, however, so I don't feel that we fully moved away from this set-up. But the conversational style of the workshop suggests so. Perhaps, this had something to do with people *doing* creative tasks as opposed to just talking. Having something to talk through – stitching activities to get

on with, whilst exploring different surgical topics. In the future, in mixed workshops like this whereby I have participants with differing roles and experiences, I would consider the numbers of participants. Is it important to have equal numbers to try to support representation and equality in conversation?

I was really grateful to the surgeon running the session in stepping outside of his formal role. I wasn't sure whether this kind of activity may be intimidating for him, being slightly outside of his day job and being uncertain as to how the workshop would go and what the patients may ask. I was lucky to find Jon as he had the technical skills to convey surgery clearly to the participants. He also had a friendly character and an openness to test new things. It was helpful that he had a rapport with the patients already, however, this was through different types of interactions in clinic. But I do feel that this helped with connecting with and engaging the women – he was a familiar face. Jon was a trainee surgeon and, perhaps, was keen to explore different formats for working. He may also have been easier to recruit to lead the session due to this. From past experience, consultant plastic surgeons have been difficult to pin down. I think that it takes a bit of time to find the right collaborators and I was only able to afford this, by having spent some time in the department as part of the residency. This, however, is not always available to Facilitators. So, mechanisms to quickly build rapport with possible collaborators is necessary. Attending or designing relevant matchmaking events may well be necessary.

Whilst I had initially tried to recruit a female surgeon to lead the workshop, I'm not sure whether this was entirely necessary. I think I was keen to explore this as most of my interactions with surgeons across my career and within the residency, had been with male surgeons (most likely due to the lower numbers of women becoming plastic surgeons). In contrast, most of the patients being treated in the context of the residency, however, were female. There's a clear disproportion of gender in both contexts. I think I was keen to see whether there was a difference in how the female surgeons related to the patients? But this is another project in itself. Something to perhaps explore in future iterations?

I realise now that the Arts in Health coordinator, who was a trained nurse in a previous life, had played an important role in the residency and supported the smooth running of the workshops. She organised presentations of my practice to the full surgical team, early on, which, I think, demonstrated to the surgeons that I had a genuine interest in their specialism. She also made sure that I had an honorary contract within the hospital trust which allowed me to dot between the different departments in the hospital, to meet the staff and get informed in quite an informal way which helped me to work out how I could develop activities that were useful for both the patients and staff there. I believe that these things also helped to recruit staff and patients to the workshops that I had designed, including the nipple reconstruction workshop. The residency was also 18 months long, on a part time basis, so it offered a good amount of time to get to know people and build a bit of trust and to allay any fears about what an Artist was going to do in their department. I felt really conscious of just *landing* in the department as an 'Artist in Residence' and people being confused or concerned about my intentions. In clinic, I remember spending a fair bit of time explaining to differing members of staff and patients, who I was, why I was there and what I was aiming to do. I got better at conveying this as the residency progressed and as things became clearer. Thinking about it, residencies have been the main way that I have practiced as an Artist as they provide focused periods of time for experimentation and exploration of subjects. I think that time is necessary not only to find collaborators, but also to assure potential future participants of your intentions, especially, in this case, as a non-clinician, of being from quite a differing specialism, not normally associated with a hospital and the services that it provides.

I'm not entirely sure if working with surgical dressings was a good or bad idea. On the one hand, it met certain technical requirements for the workshop (needing to be structured etc). It also was a material known to the surgeon. But on the other, it was still a cloth with particular clinical associations – used to treat patients and worn in recovery. I also think the synthetic nature of this material, it's plastic smell, and supposed skin tone added to its clinical-ness. If I'm trying to create a space to make patients feel comfortable, working with medical dressings possibly draws them back to experiences of illness/treatment. This was perhaps a limitation of the workshop. More time is needed to find appropriate materials for workshops like this but attention

also needs to be given to the cultural and racial associations that may be attached to particular material types. Planning the nipple reconstruction workshop definitely made me more aware of the differing material qualities of human skin and made me realise that it's quite difficult to match on a number of levels.

I thought that working with cloth, under tension, on a solid form (the table) was an interesting way of working that reflected how the surgeon may work – approaching the body from the outside in. This was a technical challenge for the women, however, as they were unable to put their hands beneath the cloth to feed the needle through – as with dress making sewing techniques. The women commented on how dissimilar surgical stitch is to stitching and mending in dress making, which some of them did at home as a hobby. We did try to feature a suturing stitch that was used in both surgery and dress making – the herringbone stitch – in the hope that this would offer a familiar reference, however, trying to do this stitch using needle holders and sutures was very difficult for the women. The fact that the women struggled with working on cloth under tension and using surgical tools has made me realise that the technical learning in the workshop was not only about exploring how a material is moved and manipulated by a surgeon but also about learning how to use the tools of the surgeons themselves. Details like the surgeon bringing along the sharps box and running the session in a surgical training room, I think, extended the surgical experience. So there is something valuable about bringing props that might be associated with the surgical technique being taught. Another reason why I think the women struggled was because of the scale of working. They were working at human scale, which I guess, in some ways, helps to connect with the site of surgery being taught, however, they said that it was fiddly. If I was designing the session again, I might consider changing the scale of the task for ease of the participants. However, how would changing the scale of the activity change the context of the surgical procedure being taught – the human body.

This was the first time that I had designed a surgical skills workshop for patients which made me a little more anxious as to how the workshop activities would be received. Previously, I had run workshops in suturing with non-patients, and also co-facilitated pattern cutting workshops with plastic surgeons. I was concerned whether the workshop had any emotional effects as most of the women had had complex surgeries

as treatment for cancer. By framing the workshop around elective surgeries practiced towards the end of the treatment pathway, I felt that we were differentiating from earlier, complex surgeries that the women may have had. Having watched a series of breast reconstruction techniques being performed in theatre, I knew that they were complex with blood supply being dissected and large flaps of skin being transitioned from donor sites to reconstruct the breast. I'm glad that the workshop took this paired back approach, featuring less invasive surgeries, especially as this was the first time that we had planned anything like this. I think this is something that needs more time and consideration, though, to carefully decide on the type of surgical method to incorporate into a workshop, and be mindful of the headspace a patient may be in when undergoing that procedure. If you're going to convey a certain type of procedure you need to consider the needs and the experience of patients who may have undergone it or may be considering undergoing it. In planning the activities, I had some understanding of this, having observed clinical consultations, and the surgeon, clearly, had a lot of experience of this. It makes me wonder whether there are more or less appropriate types of procedure to convey in a workshop like this, based on the condition and experiences of the patient. The prior knowledge that I had accrued through previous projects and early on in the residency definitely shaped my decisions around types of surgery to feature, however, this understanding was only accumulated across a significant amount of time which is not always available to Facilitators evolving their methods. It may be useful to think about ways to quickly empathise with where patients may be in a treatment pathway and understand how this may impact on them, and then use this information to frame workshop activities accordingly.

I felt that I had been able to create a less formal space for patients and clinicians to come together. As the women had the opportunity to ask lots of questions about surgical technique and experience, as they were making. I do, however, feel like there is a fine line between hosting, potentially, playful activities that at the same time, deal with difficult subject matter. Whilst some participants may use humour to make sense of experiences, some may not. I think that this is something that the Facilitator needs to be mindful of in planning the workshop, again, considering a patient's potential experience preceding any session. The Facilitator possibly also needs to assess this, in

real time, during sessions, to gauge how participants may be feeling and may be responding to the activities.

On reflection of the workshop, one woman said that seeing the 3D version of a nipple as opposed to 2D images had helped her understand the procedure, and had informed her of, exactly, how a reconstructed nipple is made and had helped her to make decisions on permanent nipples and what type she wants. Another stated that the session had helped her with closure to the cancer diagnosis, treatment and recovery process. Whereas one said that it provided her with knowledge to impart to others, should they also be interested in undergoing this procedure. I was really pleased with these outcomes of the workshop as they expanded on its original intent which was to impart surgical knowledge and create different types of conversations between surgeons and patients.

IN SUMMARY..

Through this reflection I've recognised that **the geographical location of a workshop** needs to be fit for context. If on hospital grounds, spending some time to find the right space would be beneficial to find one that works best for *all* participants (considering whether the **venue is familiar or unfamiliar** and to whom). **Planning the ratios of participants** in a workshop may also be beneficial as would **finding the right collaborators**. I also need to allow **time to sow the seeds** of a project, to build relationships with both collaborators and future, potential participants, and **consider the scale** of activities, their relevance and opportunity to simulate surgical practice. I, finally, shouldn't underestimate **the value of prior knowledge** but at the same time recognise a need to engage mechanisms to support this, if there is a lack of time available.

APPENDIX E.3. WARDROBE PROBE DATA – PARTICIPANT 2

APPENDIX E.3.1. ACTIVITY 1 – WARDROBE MAPPING

Participant 2			
Worn item	Description	Significant moment	Significance of item
1	Pink shoes	<p>Wedding day 2 years before diagnosis The 'for worse' came way too soon.</p>	<p>Grateful to [REDACTED] for sticking by me. The favourite part of my wedding outfit – resisting the traditional.</p>
2	The black and white jacket. (second hand via mums giving table)	<p>Working too hard and right through the biopsy > diagnosis window was 'on duty'. If not this jacket, another one was worn to a meeting and dinner the night before diagnosis day.</p>	<p>I used to put this on to 'feel the part' and look smart. I now feel more confident as me at work and this is just appropriate clothing as and when needed but less a part I'm playing.</p>
3	Floral dress.	<p>I remember wearing this again, 4 months after my op when I went to a festival with two friends. I felt joyful, dancing and laughing and embracing the moment. To have made it there. But also remember feeling nervous in case anyone saw my chest as I changed in the tent.</p>	<p>This dress came from a second hand clothes market in (Nairobi?). I wore it with a pink headscarf and shawl when I worked in (Somaliland?). The pattern made me happy. When I returned, I cut it off and wore it to festivals. It is a connection to the me who worked for 20 months in the desert – another time in my life – but also friendship.</p>
4	Check pyjamas.	<p>I bought these in Hammersmith TK Maxx when I was lacking time between diagnostic tests. I wasn't allowed to eat or drink. Had some kind of needle in my arm. I didn't quite know what was coming but already knew an operation was on the cards. And so Pyjamas seemed a thing I would need in uncertain times.</p>	<p>A helpful reminder that there were fewer pyjama days than I'd feared there would be. And of a time when sleep and naps came easily – Before the ***** Tamoxifen. These have been camping since, so no longer the 'sick' person PJ's.</p>
5	Maroon sports bra.	<p>Recovery at home, once the massive bruises/swelling subsided. Still have them as still have one more tattoo to get through.</p>	<p>Memories of an awful bra fitting experience at M&S. Turns out, they weren't very good sports bras when I started running in them - they rub too much.</p>
6	Navy jumpsuit.	<p>The 'bridesmaid' outfit that a sports bra and support knickers would go underneath. - 2 months after surgery (dress code navy and pink) and much deliberated over as I tried to find 'the thing to wear'.</p>	<p>I wore this with a pink hat to my friend's wedding. It was a great day. I still felt like a bedraggled, eagle and in the pictures I can see I was quite thin and tired. But I felt elegant, like I'd made an effort and comfortable to be photographed.</p>

7	<i>Paint splash blouse.</i>	<i>The baggy enough and dense enough fabric blouse but not too frumpy 'go to' for the Summer I went back to work. As a shape that didn't require cleavage but feels distinctive and not shying away/hiding away!</i>	<i>I bought it on a shopping trip with a friend and it felt good to buy something for the 'after' and to celebrate with xx after by (illegible) time with C in Winchester.</i>
8	<i>Green Hexagon coloured dress.</i>	<i>I wore this to go out with friends after lock down and it's also been to The Chelsea Flower Show and a posh birthday doo. I like wearing it as I get compliments on it. I feel it fits well, it's my style and it takes me to joyful places and company.</i>	<i>I got the fabric from a fabric shop I went to with a friend between bouts of chemo. I made this using learning from sewing classes I did during treatment and it's made to fit my new body. I shared this with a sewing community focused on post-surgery fitting. Enjoying being a Sewist.</i>
9	<i>Pink running bra (+ black skirt)</i>	<i>This is the sports bra bought for running not for surgical reasons. I won't be wearing this with pads or dressings. It is not a substitute for a real bra.</i>	<i>I bought this after completing two half marathons - slower than before surgery - but back and with the intention of continuing to run and wanting to feel confident when I run. I wanted to buy a sports bra I like. And the (illegible) is also a sign of growing body confidence.</i>

Activity 1 Garment selections. Participant 2



1.



2.



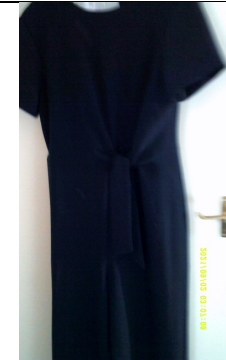
3.



4.



5.



6.



7.



8.



9.

APPENDIX E.3.2. ACTIVITY 2 – CLOTHING EVOLUTIONS

2a) Exploring evolutions of wardrobe **colour**



2b) Exploring evolutions of wardrobe **style** (P1-P6).

Wardrobe Phase	Worn Item	P2
Pre/ Diagnosis	1	<i>Vintage, bright colour</i>
	2	<i>Quirky but smart</i>
	3	<i>Cheerful</i>
Treatment	4	<i>Smooth</i>
	5	<i>Ugly</i>
	6	<i>Elegant</i>
Recovery	7	<i>Oversized</i>
	8	<i>Vintage inspired</i>
	9	<i>Sporty</i>

2b) Exploring evolutions of wardrobe **Fit** (P1-P6).

Wardrobe Phase	Worn Item	P2
Pre/ Diagnosis	1	<i>Heeled!</i>
	2	<i>Tailored</i>
	3	<i>Loosely fitted</i>
Treatment	4	<i>Baggy top, fitted waist trousers</i>
	5	<i>Compressed</i>
	6	<i>Loosely fitted</i>
Recovery	7	<i>Baggy</i>
	8	<i>Fitted</i>
	9	<i>Fitted</i>

2c) Exploring evolutions of wardrobe **Texture/Material**(P1-P6)

Wardrobe Phase	Worn Item	P2
Pre/Diagnosis	1	Suede
	2	Textured
	3	Soft/Silky cotton
Treatment	4	Smooth
	5	Soft
	6	Crepey
Recovery	7	Smooth
	8	Soft/Silky Cotton
	9	Stretchy

APPENDIX E.3.3. ACTIVITY 3 – THEN AND NOW

When looking at your completed collages: do you feel that your expectations of breast reconstruction have changed across time?

P2

Afterwards, I realise that I hadn't been aware of the non-linear nature of recovery. The vulnerability each subsequent stage thrust me into.
I'm quite angry about things I wish I'd been told before. Don't know if I could've taken them on board before. But I do wish I'd known about. Needing to know the Pantone colour of my nipples!

APPENDIX E.3.4. ACTIVITY 4 - ADAPT

Activity 4a) No content.

Activity 4b) Adapting how you wear your garments.

How has the way that you wear your clothing changed?	
P2	<p>The headscarf tubes - now get worn for running and outdoor fun, around my neck. I never chose to wear a headscarf or any hair adornments.</p> <p>Not sure if it's a change in fashions, or about something else, but short cardigans seem to have not come out of the drawers much - have lived in a denim jacket and struggled to find something to wear over Summer dresses that didn't feel frumpy. Especially when I tried a V-neck dress - a new venture for me.</p> <p>More attracted to the Scandi-aesthetic but look (illegible) when wearing something with a waist.</p>

Why has the way that you wear your clothing changed?	
P2	<ul style="list-style-type: none"> -Dressing for temperature regulation -Enjoying trying styles I might not have had the confidence to pull off before - feeling feminine enough to wear a boiler suit, or not care if I didn't quite pull it off, a V-neck dress. -I initially worried that bra/lumps and bumps would show through. Now have better bras, (illegible) settled down more, so able to wear something more figure hugging if I want - but still not skin tight. -I am choosing to still wear non-wired bras (why wreck the good work of the surgeons) but some of them still feel functional rather than joy giving garments.

4c) Documenting Practices of Discard. Have you discarded clothing items? Why? P2-5. (P1 no content).

Participant discarded...	Because..
P2	
'Woolly hats from chemo'	'Reminded me of feeling nauseous after treatment'
'Underwired bras'	'On advice of surgeon'
'Sports bras used immediately post reconstruction'	'Too big now (accommodated swelling). Was underwired and felt related to the pre me.'
'Pyjamas that were white/translucent'	'Mostly used for modesty when away - nervous lack of nipples would be seen.'
'Button through PJ tops (made by mum for post-surgery)'	'Served purpose immediately post-surgery - didn't want the reminder - have other reminders of mum's crafting skills.'

'Blue/white V-neck sundress'	'Felt too 'busty' immediately after surgery and too 'Boden' for my current style.'
'The 'chemo' cardigan'	'Served its purpose - kept me warm during treatment. Never wanted to see it again!!'
'My wedding dress'	'Mum storing for me. Her suggestion. Decision to be made but feels less emotive than the things above'

4c) Do you adapt your clothing to differing contexts? How? Why?

	P2
Personal Contexts	<i>Firmly (illegible) the slobbering around in jogging pants - NOT A PATIENT! Have a pair of yoga pants for Pilates and running tights but apart from PJ trousers and hoodie on a lazy Sunday morning, prefer to be 'dressed' even if it's just old blue jeans.</i>
Recreational Contexts	<i>Making the most of dressing up for parties, meals. But also picking things that I love or I made rather than blending in - celebrating life, friends. More figure hugging running gear - I feel more body confident. And exercise is more important to me, a form of medicine - preventing the 'C' coming back. Higher cut top to swimsuit - additional back strap.</i>
Professional Contexts	<i>Have one or two outfits I've had compliments in – E.g. Grey Hepburn-esque dress - wear these when I need to feel 'on my game!' More distinctive glasses - bigger - at first in response to the short hair. Due to Covid, have only had to attend one formal evening event - for this I was very 'covered up' - boat neck, long sleeves. It would be interesting what I feel comfortable to wear now. Returning to wearing heels now. Immediately post chemo/op too difficult. But heeled boots rather than formal court shoes - more casual approach, less city smart.</i>
Additional Comments	<i>In all areas, layering has been important - temperature control is so hard and in the Summer in particular, the Tamoxifen induced hot flashes have been particularly hard to deal with. However, I've been keen to do this without looking like someone who shops at Hampstead Bazaar or Per Una. Looking for more tailored pieces, simple pieces rather than floaty or frilly!! Initially, after treatment, wore a lot of veil tops to 'cover up' under blouses/T-shirt. Feel more (comfortable) to go without them now.</i>

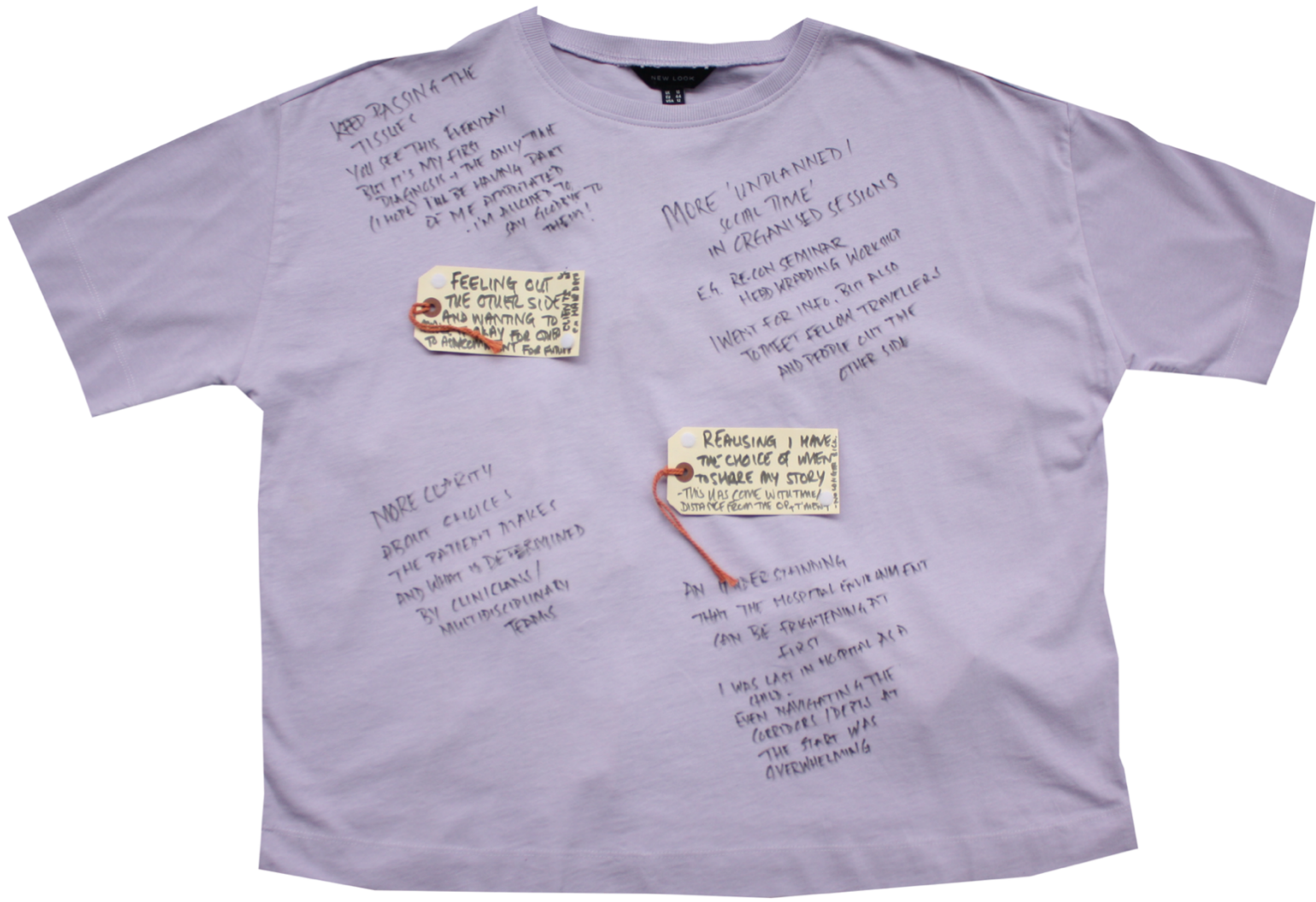
4d) Thinking about your future wardrobe

Participant	Do you for see making any adaptations to your wardrobe in the future?
P2	<p>(Thankfully) No more zip front bras!</p> <p>Some of my work I have to do international travel. Modesty garments will be needed out. But that's as much in relation to Covid as it is to processing of my cancer journey.</p> <p>I'd like to continue weeding out garments that I don't like wearing anymore.</p> <p>At the moment I'm enjoying making the most of my flatter stomach but anticipate there will be further style shifts as my waist thickens more with age.</p> <p>Very focused, at the moment, on not 'dressing old.' What that feels/seems to me I am sure will change over the coming years.</p>

APPENDIX E.3.5. ACTIVITY 5 – OUR PUBLIC AND PRIVATE SELVES

Exploring complex topics of conversation and mapping ideas for how to best support these conversations, in the future.





KEEP PASSING THE
TISSUE!
YOU SEE THIS EVERYDAY
BUT IT'S MY FIRST
DRAWING - THE ONLY TIME
(I HOPE) I'VE BE HAVING PART
OF ME DIVERSIFIED
I'M ALLOWED TO
SAY 'HELLO' TO
THEM!

FEELING OUT
THE OTHER SIDE
AND WANTING TO
TO PLAY FOR CAR
TO PROMOTE FOR RAIN

MORE 'UNPLANNED'
SOCIAL TIME'
IN CREATISED SESSIONS
E.G. RE-CON SEMINAR
HEED WRAPPING WORKSHOP
I WENT FOR INFO. BUT ALSO
TO MEET FELLOW TRAVELLERS
AND PEOPLE ON THE
OTHER SIDE

REUSING I HAVE
THE CHOICE OF WHEN
TO SHARE MY STORY
- THIS HAS COME WITH TIME/
DISTANCE FROM THE OP.TMNT

MORE CLARITY
ABOUT CHOICES
THE PATIENT MAKES
AND WHAT IS DETERMINED
BY CLINICIANS /
MULTIDISCIPLINARY
TEAMS

AN UNDEFINING
THAT THE HOSPITAL ENVIRONMENT
CAN BE FRIGHTENING AT
FIRST
I WAS LOST IN HOSPITAL AS A
CHILD -
EVEN MANAGING THE
CORRIDOR I'D BE IN
THE START WAS
OVERWHELMING

WHAT THIS DOES
TO ME AS A
SEXUAL BEING

GENETIC TEST
- POTENTIAL
IMPLICATIONS

LOSS OF
INTELLECTUAL
STIMULATION /
BRAINPOWER DURING
TREATMENT

P2			
Internal tags Difficult topics to discuss	External tags Topics now able to discuss	What has enabled you to talk about these topics?	Suggestions for supporting these conversations in the future
<i>That I feel so grateful to be alive but miss my old body</i>			<p><i>Keep passing the tissues, you see this everyday but it's my first diagnosis and the only time, I hope, I'll be having part of me amputated - I'm allowed to say goodbye to them!</i></p> <p><i>More 'unplanned' social time in organised sessions E.g. Recon seminar, head wrapping workshop. I went for info but also to meet fellow travellers and people out the other side.</i></p> <p><i>More clarity about choices the patient makes and what it determined by clinicians/multi-disciplinary teams.</i></p> <p><i>An understanding that the hospital environment can be frightening at first. I was last in hospital as a child. Even navigating the corridors/dept's at the start was overwhelming.</i></p>
<i>What this does to me as a sexual being</i>			
<i>Loss of intellectual stimulation/brain power during treatment</i>			
<i>Sharing initial diagnosis</i>			
<i>That it might come back</i>			
<i>Which type of recon - single, double mastectomy</i>			
<i>Genetic test - potential implications</i>			
<i>Hair loss</i>	<i>Hair loss</i>	<i>Feeling out the other side and wanting to make it okay for others to ask/comment for future clients E.g. Hairdressers.</i>	
<i>Privacy vs support</i>	<i>Privacy vs support</i>	<i>Realising I have the choice of when to share my story. This has come with time/distance from the op and t'ment. No longer sick.</i>	

APPENDIX E.4. WARDROBE PROBE FEEDBACK FORMS –
PARTICIPANT 2

APPENDIX E.4.1. FEEDBACK FORM ACTIVITY 1 – WARDROBE
MAPPING

<p>1. How did you find doing these exercises? (Wardrobe Mapping - Participants selected 9 worn items from their wardrobe - 3 that represent pre, 3 during and 3 post treatment. They then completed a hanger for each item, asking them to consider how and why these items were significant to them.)</p>	
P2	<p>This took me a long time to get started (10 days after the zoom call) but I guess the 'selecting' had been playing through in my mind through all that time. Once I actually started pulling the items out of my wardrobe, choosing between a couple of things I found I was enjoying the process. And in particular I enjoyed the writing of the hanger stories. I am now looking forwards to the next exercise.</p>
<p>2. What did you enjoy most about these exercises?</p>	
P2	<p>-Writing the hanger stories. -Being able to put some items aside 'They weren't the most important story' - particularly liberating for the chemo scarves! -Enjoying the 'now' garments and stories with them. And that they show celebrations and friendships and people, but also noticing that before stories involved (illegible) stories too.</p>
<p>3. What did you enjoy least?</p>	
P2	<p>For the before garments, in particular, I found it difficult to decide between the 'significance to me' and the 'significance/where in the diagnosis process' questions. I found identifying the before outfits most challenging.</p>
<p>(Do you have any recommendations for how the exercises can be improved?)</p>	
P2	<p>But that may also be a reflection of doing this exercise two and a half years on - so some of the stories/memories are less relevant and, well, because of Covid - how many of the stories from then to now in my wardrobe are because of that instead?</p>
<p>What are your thoughts on the concept for these exercises?</p>	
P2	<p>Noticing that the chemo journey is quite enmeshed with the reconstruction journey for me, but for this exercise I focused most on associations with my body rather than how. I think this is a helpful way of recollecting occasions and moments before, during and after.</p>

	<p>The 'narrow it down to 9' (items) is helpful but felt like a hurdle. Maybe some flexibility e.g. 2-4 to each time zone - max 10?</p> <p>Important to frame in 'uncover some of the story/see if there is a story'. Different garments pulled out would say different things - equally valid.</p> <p>However, just doing the exercise has shifted something today for me, so I feel that there is a (illegible) in it as an exercise.</p>
<p>5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?</p>	
<p>P2</p>	<p>Yes. Realising that the 'in treatment clothes' don't make me upset and I now see them as armour for an experience I'm glad and proud of being the other side of. I would not have registered this without this exercise. And I didn't feel this way at the time I bought or first wore them.</p> <p>A very deep gratitude to those who (illegible) with me (illegible) came up. And in particular for my husband - this brought up emotions. A helpful reminder.</p> <p>Noticing where I've gotten to now. How my clothes choices show me practicing self-care/body positivity and realising that my limitations on what I could wear immediately after surgery are now more of an (illegible). No V necks.</p>

APPENDIX E.4.2. FEEDBACK FORM ACTIVITY 2 – CLOTHING EVOLUTIONS

<p>1. How did you find doing these exercises? (Clothing Evolutions - Participants photographed chronological collections of their clothing that they had gathered in activity 1 and were asked to reflect on whether the colour, cut or cloth of their worn items had changed across these collections.)</p>	
P2	It was fun to look at the colour swatches. I am not sure that the samples I chose for exercise 1 necessarily were the items that would have (illegible) any changes in style in my wardrobe (I can think of other examples of quite different styles that I tried after treatment.)
<p>2. What did you enjoy most about these exercises?</p>	
P2	Thinking about colour and trying to discern if that had changed.
<p>3. What did you enjoy least?</p>	
P2	Trying to pick one word for the exercises. Particularly in describing textures, I felt like I needed more than one. I wanted to use the fabric name E.g. Linen and a texture.
<p>(Do you have any recommendations for how the exercises can be improved?)</p>	
P2	I am not sure that there was much distinction between style and fit.
<p>What are your thoughts on the concept for these exercises?</p>	
P2	For me, particularly with the same garments as exercise 1, although it was interesting to see what would come up, it didn't particularly reveal any more. I will keep noticing if other new items in the wardrobe do demarcate a degree of style, fit or texture. So it's made me aware and given me a tool to think about it with.
<p>5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?</p>	
P2	This exercise, not so much...I think I got more from the first exercise. It was reassuring to note that two of the three after treatment garments are well fitted - showing a confidence to care for my after cancer and reconstructed body.

APPENDIX E.4.3. FEEDBACK FORM ACTIVITY 3 – THEN AND NOW

<p>1. How did you find doing these exercises? (Then and Now - Participants selected a collection of materials from their home as well as from materials provided in their probe pack. They then drafted simple garment pattern panels (front and back) from a select worn item from their wardrobe, onto which they collaged their expectations of breast reconstruction surgery - pre and post-operatively.)</p>	
P2	<p>I was not looking forwards to this exercise and put it off. However, once I started I found I enjoyed particularly the front/after image. I found it hard to honestly put myself back into the before stage as this is so coloured by the reality of the post-surgery experience.</p>
<p>2. What did you enjoy most about these exercises?</p>	
P2	<p>The 'after' gave me an outlet to convey some thoughts and emotions that I hadn't clearly articulated before.</p>
<p>3. What did you enjoy least?</p>	
P2	<p>Not sure collage is my medium. This would have been better in a craft room than on my lounge floor.</p>
<p>(Do you have any recommendations for how the exercises can be improved?)</p>	
P2	<p>No content</p>
<p>What are your thoughts on the concept for these exercises?</p>	
P2	<p>I think it could be good to also have a question about the garment that you made the pattern from. Feels like an interesting concept that didn't come through to the exercise itself. The back, maybe does represent the 'past' but much thinking of before the (op) definitely focused on the breasts and tummy - so very much front of me.</p>
<p>5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?</p>	
P2	<p>In the context of making a piece of art, I found that I could articulate something I'd been angry about, some things I'm proud of, some (illegible). It did unlock some things for me. However, within the framework of creating a piece of art, which in this case, others will see, there is some censoring for others to understand. I think I'll come back to these when I get them back and see if there's more for me to uncover in this exercise.</p>

APPENDIX E.4.4. FEEDBACK FORM ACTIVITY 4 – ADAPT

<p>1. How did you find doing these exercises? (Adapt - Participants completed a series of exercises that required them to document alterations made to individual garments as well as to overall style within the wardrobe. Other adaptations to the wardrobe included the documentation of discarded items, in addition to speculations on aspirational wardrobes for the future.)</p>	
P2	<p>This is really hard to do when so much of what I wear now has also been impacted by post-lockdown changes to work and more hybrid working. Really not sure what is 'treatment' related and what is societal.</p>
<p>2. What did you enjoy most about these exercises?</p>	
P2	<p>It was helpful to document the things that got thrown away. Some of them, at the time, were painful, or I deliberately got rid of things before then because painful. It is interesting to notice that they're less painful/emotive now. And actually good to see that things that came to me, during the acute phase of treatment, have passed out of my life again.</p>
<p>3. What did you enjoy least?</p>	
P2	<p>Realising that I have more wardrobe weeding to do!</p>
<p>(Do you have any recommendations for how the exercises can be improved?)</p>	
P2	<p>It may be useful to have a bit more of a 'ritual' around the things that were gone - particularly if doing this mid or quite soon after treatment.</p>
<p>What are your thoughts on the concept for these exercises?</p>	
P2	<p>I found the exercise helpful but am not sure that I was properly able to draw it back to 'personal adjustments in my life' – It may be helpful to reflect on this first – somehow it feels a bit similar to the style exercise 2? I found the thinking forward exercise hard to connect with – it may be that this comes to life more as I reflect on it in the future.</p>
<p>5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?</p>	
P2	<p>It has been helpful to finally 'let go' of the things that went. It has been helpful to try to articulate how my approach to clothes has changed or what my values are around clothes. (E.g. Elastic waists are for patients, I'm not a patient now!) Again, some of the garments have stories of me in relation to others. I've enjoyed feeling gratitude for the people in my life. E.g. The friend who made the emergency run to M&S as no-one told me about post-surgery bruising and I had the wrong size bra.</p>

APPENDIX E.4.5. FEEDBACK FORM ACTIVITY 5 – OUR PUBLIC AND PRIVATE SELVES

<p>1. How did you find doing these exercises? (Participants identified complex topics and wrote these onto a series of tags that they attached to the inside of a garment. They were then asked to select which topics they now felt able to discuss, post operatively, and moved the corresponding tags from the inside of the garment to the outside; writing on them what had enabled them to talk about these subjects. Finally, the participants wrote their recommendations for future opportunities to support conversations around these topics onto the outside of the T-shirt.)</p>	
P2	<p>I found this exercise hard but important. It gave me a nudge to think through what still remains difficult to discuss. The exercise of moving a label to the outside was good as it felt 'active'. And for me, then also (illegible) a change (illegible) of being in a different place. I enjoyed the 'graffiti' aspect of the exercise d).</p>
<p>2. What did you enjoy most about these exercises?</p>	
P2	<p>I like the concept of naming things that remain hidden inside the T-shirt. I liked that there wasn't a limit to the number of labels. (well there was in the supply) but that being able to write down 10 or more things of varying importance helped me.</p>
<p>3. What did you enjoy least?</p>	
P2	<p>The Velcro dots feel a bit 'fiddly'. I wasn't sure about the significance of the T-shirt although do like the concept of putting demands on the outside - protest T-shirt - but then lilac feels too softer colour for this.</p>
<p>(Do you have any recommendations for how the exercises can be improved?)</p>	
P2	<p>I am wondering if I did this exercise with a garment from treatment that I was planning to throw away if that would have been more helpful - given a bit of ritual to that act.</p>
<p>What are your thoughts on the concept for these exercises?</p>	
P2	<p>I found this a helpful exercise. I would have been interested to see how this would have been to do this with a bra as the garment. The concept of finding a 'hidden' way to articulate hidden/hard things to talk about was powerful. This was a different framing of 'what feedback do you want to give us' for clinicians. It felt easier in this way to be specific and demanding!! Assertive.</p>
<p>5. Have these exercises helped you to reflect on your experiences of primary breast cancer in new ways? If so, how?</p>	
P2	<p>Yes, it has. I had not fully acknowledged all the aspects that I had still not found ways to talk about. It was also a helpful time to check in on what I still want to keep private/hidden. It enabled me to acknowledge some choices I've made to be more open. I found the exercise more engaging than just answering the questions would have been.</p>

APPENDIX E.5.WARDROBE PROBE FOCUS GROUP – SERVICE USERS

00:00:34.910 --> 00:01:05.300

Rhian Solomon

Well, I really appreciate it and the first thing you know I wanna say thank you to everyone. So from being able to make this time obviously to meet today 'cause I know it's like a really mad time with Christmas and the lead up with all the preparation and everything and obviously the time that you spent over the last few weeks. So it's a big ask that there's been of me on and a big sort of a request on your time. So I'm I. First of all wanted to really say I'm really grateful.

00:01:05.960 --> 00:01:21.490

Rhian Solomon

Uh, before we crack on with any of the questions I'm obviously going to be leading the session today, but Nic is obviously here as well and Nic is gonna be talking a little bit later on about emotional support available beyond today.

00:01:22.150 --> 00:01:32.540

Rhian Solomon

Uh, so we can talk a little bit about that. I think there's going to be quite a lot of talk about, and there's just a couple of things before we kind of crack on with the questions.

00:01:33.210 --> 00:01:45.370

Rhian Solomon

Uh, so what you probably notice is that the questions in your activity packs with those feedback forms that you are completing. The questions were quite practical, asking you about what worked, what didn't.

00:01:46.260 --> 00:02:11.560

Rhian Solomon

Uhm, how things could be improved. What you have probably gathered from the focus group questions that I sent through that today is a slightly different tact in that I guess I'm getting us to sort of delve a bit deeper into the significance of using our clothing and whether there are benefits of using clothing in a creative way to reflect on experiences of breast cancer. So you probably notice that it is quite different.

00:02:11.970 --> 00:02:12.780

Rhian Solomon

Uhm?

00:02:13.680 --> 00:02:32.680

Rhian Solomon

A different focus with the feedback if you like, but there's gonna be a lot of blurring between the two to be honest. There's obviously no right or wrong answers at all, and I want everyone to speak as openly as you feel comfortable with, but I'm very aware that you know the packs have delved into some personal content.

00:02:33.710 --> 00:02:42.400

Rhian Solomon

And for some people, potentially so I think I want you to be mindful of you know what you feel comfortable with sharing and what you don't. I think that's really important.

00:02:43.110 --> 00:02:44.730

Rhian Solomon

I want you to be critical.

00:02:46.450 --> 00:03:07.740

Rhian Solomon

Don't hold back. Don't think that you're gonna offend me. All feedback is really good feedback in the sense that all of the information that I can gather from the activities or from the focus group is going to help me to make decisions about whether these activities are beneficial really on what works and what doesn't. So don't hold back or think you're going to offend me.

00:03:09.040 --> 00:03:18.360

Rhian Solomon

Has everyone got their packs to hand, I thought I'd kind of recommend that just 'cause it helps as a bit of a prompt.

00:03:19.730 --> 00:03:32.050

Rhian Solomon

Right, I think what we'll do is we'll kind of crack on with the first question, which is very open question, so how did you find using this this pack?
00:03:34.380 --> 00:03:35.230
Rhian Solomon
How did it go?
00:03:38.840 --> 00:03:41.350
Participant 3
Do you want any of us in particular to talk?
00:03:41.280 --> 00:03:41.720
Rhian Solomon
No.
00:03:41.920 --> 00:03:45.720
Rhian Solomon
Not at all like, whoever wants to, you know, jump in there.
00:03:48.800 --> 00:03:50.550
Participant 3
Um, well I could say.
00:03:51.740 --> 00:04:01.940
Participant 3
I think as I started it, 'cause I'm quite old. Yeah, let's just start and I'm just gonna work my way through this. Really sort of power through and then um...
00:04:02.820 --> 00:04:05.670
Participant 3
My husband noticed my mood changing a bit.
00:04:06.580 --> 00:04:07.290
Participant 3
And.
00:04:08.240 --> 00:04:37.410
Participant 3
I don't know that I was conscious of it at first, but I think when it brought up thoughts that..This for me.. I'm very someone who's like Oh yeah, think about something. Put it in the drawer, shut the draw and then open the door when you need to. But suddenly these draws were opening and I didn't realize and I think it was well he could see it. Not that I was moody, but he just noticed a difference in me and I think it's when you're thinking.
00:04:38.370 --> 00:04:51.130
Participant 3
Before surgery, before things happen and you have to then go back to that time. I've left that time because for me my surgery was five years ago for, well, my mastectomy was not the other surgeries, but.
00:04:51.860 --> 00:04:59.840
Participant 3
That was five years ago and leading up to it, there was a lot that happened on the way, so suddenly to go back to that time.
00:05:00.690 --> 00:05:21.900
Participant 3
It, it just..it.. I don't know about the rest of you, but at that time there's like a little something in your brain that never quite switches off because there's always something in the back of your mind. But what's the next biopsy? What's this? What's that? And then suddenly my head went back to that space, and it wasn't comfortable to be there, I think.
00:05:23.940 --> 00:05:28.430
Participant 4
Yeah, I can relate to that. I've been quite like a moody teenager at times.
00:05:30.150 --> 00:05:34.040
Participant 4
You know, sort of all over the show, and even this afternoon, just.
00:05:30.950 --> 00:05:31.550
Participant 3
Yeah.

00:05:34.810 --> 00:05:36.090
Participant 4
Talking about stuff, but I.
00:05:36.870 --> 00:05:40.570
Participant 4
I found it really difficult to get started.
00:05:39.770 --> 00:05:40.760
Participant 3
Me too
00:05:41.480 --> 00:05:42.250
Participant 4
Uhm?
00:05:43.090 --> 00:05:49.900
Participant 4
Yeah, choosing the clothes, but then I think it's the third activity where you make the.
00:05:50.580 --> 00:05:52.740
Participant 4
The top, with the collage.
00:05:54.380 --> 00:05:57.760
Participant 4
The collage I spent a lot of time on that and I and I.
00:05:54.480 --> 00:05:54.780
Rhian Solomon
yeah.
00:05:55.130 --> 00:05:55.720
Rhian Solomon
Third one.
00:05:59.200 --> 00:06:01.020
Participant 4
Yeah, that brought up an awful lot of stuff.
00:06:02.900 --> 00:06:07.310
Participant 4
But yeah, getting started it was sort of like get it out, put it away.
00:06:07.970 --> 00:06:09.530
Participant 4
And it is oh don't wanna think about that.
00:06:11.070 --> 00:06:12.130
Participant 4
Put that back in the cupboard (laugh)
00:06:15.540 --> 00:06:37.780
Participant 6
Well, I said it might just make me feel tired when I started. I thought it was going to be quite easy to do and then when I started it, I thought gosh, this is really tiring. Just going through everything and then actually I told Rhian I did actually in the start of the whole project in the first week I did have to have a biopsy. It turned out to be fine but that kind of completely threw me. 'cause then I was. I was sort of set off in a different.
00:06:38.600 --> 00:06:41.720
Participant 6
I couldn't concentrate at all for like the first week and a half.
00:06:41.770 --> 00:06:42.410
Participant 6
Uhm?
00:06:43.460 --> 00:06:58.110
Participant 6
But it's fine. There's nothing wrong at all. It's just fat necrosis. It turns out, but uhm, yeah, so that didn't get off to the best of starts, and I thought it was all going to be a breeze. If I love the creative side bits, they were my favourite bits. In fact I spent way, way too long on those. Because I love doing them.

00:06:59.770 --> 00:07:04.490
Participant 6
And I actually found..I thought I'd find the back hard (Activity 3 - Collage) but actually found it quite easy.
00:07:05.190 --> 00:07:05.750
Participant 6
I think.
00:07:06.740 --> 00:07:16.560
Participant 6
I think partly because it was 2, well over 2 years ago that I had my surgery so, but it's all relatively quite fresh in my mind as well. Like I can think of every little detail.
00:07:17.170 --> 00:07:17.800
Participant 6
Uhm?
00:07:19.570 --> 00:07:48.600
Participant 6
And because I was given options like seven days before I had surgery. I was given so many options, you can have this, this, this or this. I was like, I was like a rabbit caught in headlights and it brought all that emotion out like I've got to make this decision and I've only got 7 days to decide what it's going to be. That's going to influence the rest of my.. technically. The rest of my life. Really. So that brought all that out or what do I choose? What's what? What's the best for me? All those kind of anxieties? So that was quite interesting in itself.
00:07:49.790 --> 00:07:55.110
Participant 6
There's. The front was probably easier in that respect, 'cause it was more positive I guess.
00:07:56.640 --> 00:08:02.670
Participant 6
But yeah, just just generally, I felt the whole thing. I was just saying I left some of it until this morning because I.
00:08:04.500 --> 00:08:12.770
Participant 6
I wanted to think it through like I didn't want to commit myself to stuff and so I've left it right to the very last minute. To write down some of the more.
00:08:13.410 --> 00:08:16.020
Participant 6
Uhm, emotional stuff I guess.
00:08:16.640 --> 00:08:18.490
Participant 6
I wanted to work through what I wanted to say.
00:08:18.540 --> 00:08:20.150
Participant 6
I yeah.
00:08:21.270 --> 00:08:26.940
Participant 6
But yeah, I thought it was gonna be dead easy..I thought it's gonna be easy. But actually it wasn't easy at all..
00:08:27.950 --> 00:08:28.440
Participant 6
To be fair.
00:08:30.570 --> 00:08:38.410
Rhian Solomon
How did you find that process of selection, you know? Some of you have said that it was really quite difficult revisiting.
00:08:38.490 --> 00:08:48.150
Rhian Solomon
potentially earlier phases of diagnosis and treatment. And how did other people find that process?
00:08:48.320 --> 00:08:53.350
Rhian Solomon
Of selecting out the nine.

00:08:54.730 --> 00:08:56.010

Rhian Solomon

Items (of clothing), let's say.

00:08:59.040 --> 00:09:29.500

Participant 5

I think like when I did mine like I found it like relatively straightforward like in the extent. To cut a long story short, like my wardrobe got compressed like over the last like just before like 2019 'cause I was living abroad and I came back to the UK and so I I kind of threw a lot of things out and so there wasn't actually very much in my wardrobe anymore. If that makes sense. So it was kind of easier just to kind of pull things out and it didn't take as long. I think maybe it's if say if you have like a really big wardrobe.

00:09:29.550 --> 00:09:37.680

Participant 5

But then, having said that, like I, I think I I remember distinctly struggling with the kind of before time.

00:09:38.590 --> 00:10:08.450

Participant 5

I don't. I don't know why exactly, but just trying to pick out something that symbolized something or made sense to me in that moment. Like it really, it like I spent a lot of time really having to sort of really think that through. Whereas like in the during, it made.. it was more obvious to me it was like, oh, here is the pyjama pants that I wore? Like? Probably like on and off for like definitely, continuously for like 9 months or something. Or here is like here's the you know the bra that they give you post-surgery to kind of keep everything together and that just seemed like.

00:10:08.490 --> 00:10:24.620

Participant 5

That just seemed quite clear to me, and then the post time again. I think there was another one where it was like I need a bit more time to think these things through and like you know what *does* represent the post time for me and so.

00:10:25.440 --> 00:10:29.990

Participant 5

Yes, I guess that's so, maybe I'm contradicting what I said at the beginning by saying that now.. but.

00:10:31.120 --> 00:10:32.390

Participant 5

Yeah, that was my experience anyway.

00:10:33.570 --> 00:10:54.140

Participant 4

One of the items that I picked out was a bra that I decorated for the Moonwalk in 2016 and I hadn't really thought about it. A little less started doing this 'cause I chose it because obviously at the time I was walking for my sister, my friend. My next door neighbour, who had all had breast cancer, other women who had breast cancer.

00:10:54.930 --> 00:10:55.580

Participant 4

Uhm?

00:10:56.200 --> 00:11:02.780

Participant 4

How little you know there it was coming down the tracks for me in the future, but it struck me when I when I.

00:11:03.870 --> 00:11:05.790

Participant 4

Was looking at it this time, it's actually.

00:11:06.580 --> 00:11:12.200

Participant 4

When I went for my um.. 'cause, mine was my really, picked up on my second routine mammogram.

00:11:13.070 --> 00:11:14.240

Participant 4

And when I went in.

00:11:14.850 --> 00:11:25.670

Participant 4

For the results and they said, here you are in in 2015 can you see it then? And it was starting then and they showed it me. so when I was doing the Moonwalk for all these other women.

00:11:26.860 --> 00:11:28.790
Participant 4
Mine was already there waiting for me.
00:11:29.080 --> 00:11:29.590
Participant 5
Yes.
00:11:29.510 --> 00:11:29.730
Participant 3
Yeah.
00:11:30.400 --> 00:11:31.080
Participant 4
Uhm?
00:11:31.860 --> 00:11:36.870
Participant 4
Yeah, and that was quite strange to think that you never know what's coming, but yeah.
00:11:39.260 --> 00:11:40.890
Participant 4
It was er it was.., yeah.
00:11:42.050 --> 00:11:47.130
Participant 4
Interesting when you start to sort of reflect on things and you think, well, you don't know what life's got in store for you.
00:11:49.180 --> 00:11:51.570
Rhian Solomon
How did you feel about seeing the whole nine?
00:11:52.520 --> 00:12:04.660
Rhian Solomon
Like 'cause obviously you had to select from different stages as well, but seeing the line as a collection together. How did people maybe feel about having that chronology, if you like?
00:12:05.040 --> 00:12:14.060
Rhian Solomon
All those different periods, is it more useful to look at as a whole as opposed to segments or?
00:12:15.620 --> 00:12:18.440
Participant 2
I think something that came up for me was.
00:12:19.100 --> 00:12:50.880
Participant 2
lots of the clothes during and after remind me of people and say like one of the things was what I had to wear to be a bridesmaid. Like soon after surgery but that was also kind of a celebration of I was at a wedding that I might not have been at. So I think I think for me although the clothes were the hook the story it told for me was a bit about.
00:12:51.210 --> 00:12:59.460
Participant 2
People being there with me and and the kind of looking at the things last feeling.
00:13:00.170 --> 00:13:03.410
Participant 2
I guess 'cause I pick the things that I like most about..
00:13:04.110 --> 00:13:34.230
Participant 2
my wardrobe at the moment, so that's my most confident recovered me, so I've found the going back to the before both on there (activity 1) and on the back (activity 3 collage) really difficult. And yeah I guess similar to other people that maybe hasn't been something I'd have done willingly and not sure genuinely how helpful that is doing that.
00:13:34.660 --> 00:13:39.760
Participant 2
This much time on, um, but time will tell I guess yeah.
00:13:42.500 --> 00:13:47.750
Rhian Solomon
Does anyone else want to add anything about that that's in process of selection?

00:13:49.500 --> 00:13:50.150
Participant 3
Thanks.

00:13:50.210 --> 00:13:59.250
Participant 3
For me, the earlier items, not even the in between stage, but the beginning. It was just hard I think because.

00:14:00.040 --> 00:14:05.290
Participant 3
That part of your body is such that time in your life is. It's just different now.

00:14:06.080 --> 00:14:06.770
Participant 3
Uhm?

00:14:08.340 --> 00:14:10.250
Participant 3
It has helped me in that.

00:14:11.170 --> 00:14:20.080
Participant 3
I see things slightly differently, even just with your project as I mentioned to you earlier that I've gone in and got my first prosthesis, which I didn't have before.

00:14:20.130 --> 00:14:48.020
Participant 3
Or, uh, but I think that my clothes are happier now when I look at my clothes, there's definitely more colour and maybe the texture, they're a little softer and I didn't have any of these kind of fitted dresses that I would have worn pre surgery. I haven't got any, I found it quite hard to find things you know a nice top I used to wear to work, which I would still wear now, but my old wardrobe.

00:14:49.150 --> 00:14:56.030
Participant 3
It's kind of almost non-existent in the smarter things that I would wear because they weren't relevant to my body anymore.

00:14:56.800 --> 00:14:59.330
Participant 3
And also I think I don't know with anybody else but.

00:15:00.110 --> 00:15:08.570
Participant 3
I had quite a large chest before my mastectomy, so I had to have symmetry as well, so that's another level because.

00:15:09.270 --> 00:15:35.060
Participant 3
You know I always had this big chest and then suddenly for however many months I had my implant and then I had my original breast. Now my original breast was changed, then it was changed again because I had an issue with my implants. So and yeah and it will change again because my implants have been taken off the market and so it's all of those. It's not. It's not just you have your surgery and what you gonna wear now. It's lots of thoughts about.

00:15:36.400 --> 00:15:45.250
Participant 3
How you view that part of your body so my new clothes are my happy space because I now dress to suit my body as it is today.

00:15:45.890 --> 00:15:50.650
Participant 3
So, I think finding the older clothes is difficult because that's not.

00:15:51.450 --> 00:15:56.110
Participant 3
You know, certainly tighter things and so on. It's not how I would choose to dress today.

00:15:58.450 --> 00:16:00.170
Participant 3
Did that make sense like that makes sense?

00:16:01.840 --> 00:16:05.650

Participant 6

I actually had this little sense of 'cause I actually feel better.

00:16:06.410 --> 00:16:15.250

Participant 6

about myself now, 'cause like I was quite lucky. I think 'cause I've quite big boobs and I'm not. I'm not very big. I'm not very tall so I actually had a.

00:16:16.170 --> 00:16:31.490

Participant 6

oh what they called, a mammoplasty, so it's actually like a breast lift and a reduction. So I was lucky to be able to have that I guess, but I do feel a little bit of a sense of guilt about that because I do feel kind of better off than I was beforehand. So when I looked at my dress that I first took out the wardrobe, but number one in the list.

00:16:32.400 --> 00:16:33.550

Participant 6

It's actually.

00:16:34.620 --> 00:16:37.130

Participant 6

I bought that dress in 2007.

00:16:39.050 --> 00:16:44.930

Participant 6

Yeah, I mean it's it's actually too big for me now and it was a dress that was very fitted and I wore to work.

00:16:47.060 --> 00:17:09.890

Participant 6

I've kind of gone from here to here with this bit in the middle, which is where I wore big, baggy things and floppy things and now I'm kind of getting into the things that I wore back in 2007 and I feel very lucky that I was able to have that kind of surgery 'cause I know it's not possible for everybody to do that. So when I talk to people I feel a sense of a little bit of guilt about that, but I can't do anything about it.

00:17:11.070 --> 00:17:15.950

Participant 6

So people are worse off than me. That's what I'm saying, so I don't think there is an element of.

00:17:17.110 --> 00:17:21.380

Participant 6

Sadness I guess 'cause I know some friends that haven't been able to do things like that.

00:17:23.090 --> 00:17:25.310

Participant 2

I hear that in kind of cause I had.

00:17:25.760 --> 00:17:46.030

Participant 2

from my stomach the reconstruction and so, whilst up here is not everything it might be I now have a flat stomach which a woman of my age shouldn't have, and therefore there's some clothes that I can wear now that I would have felt really self-conscious about wearing before. So yeah.

00:17:35.180 --> 00:17:36.240

Participant 6

Yeah, that was one of my options but I chose not to have that. yeah

00:17:50.230 --> 00:18:08.420

Rhian Solomon

Do you think that like with the activity also thinking about it in the future, I guess is that you think it's better to not look at clothing from before or from the diagnosis period. Do you think that it's too difficult to return to that period and that it potentially should?

00:18:09.880 --> 00:18:18.020

Rhian Solomon

I didn't know, I guess not feature as part of the process. Or do you think that it's important to reflect on that period?

00:18:18.950 --> 00:18:19.770

Rhian Solomon

I'm wondering.

00:18:20.740 --> 00:18:22.830

Participant 6

For me it wasn't so much about me.

00:18:23.500 --> 00:18:24.780

Participant 6

Those things I looked at.

00:18:25.390 --> 00:18:41.400

Participant 6

Because my husband died in 2011 of cancer, So looking at the things before are more to do with my relationships with him and things that I did with him. Than they were technically about me. So that for me that was more difficult in that respect, but.

00:18:43.210 --> 00:18:47.370

Participant 6

I don't know. I suppose if everybody is different aren't they. I wasn't. Yeah, I don't know.

00:18:49.320 --> 00:18:52.250

Participant 6

So I suppose that's why it made me feel quite sad in some ways.

00:18:53.040 --> 00:19:02.280

Participant 6

Things we used to do and like a particular dress. I picked a cocktail dress that we used to go out and do stuff. You know so that was my #2 item and that kind of brought back.

00:19:03.900 --> 00:19:07.400

Participant 6

More memories than just the breast cancer for me. That was the problem I think.

00:19:08.510 --> 00:19:10.850

Participant 6

As you say, it's to do with people and memories and.

00:19:11.470 --> 00:19:14.270

Participant 6

Uhm, other people in your life, probably.

00:19:16.130 --> 00:19:19.170

Participant 5

I think that you know, even though it was sort of.

00:19:19.760 --> 00:19:49.860

Participant 5

Yeah it was challenging and it was something that you know I was having to really think very deeply about like who I was in the before time and especially I think with me, you know I was. I was diagnosed when I was 34 so you know just thinking about like for me like one thing, I find myself doing, it's like seeing the before time as like my youth, I guess. And then like and then this is kind of now I'm not, I'm 36 now. I'm not like particularly old or anything but there's just like that. Just like psychically and like emotionally like it.

00:19:50.160 --> 00:20:21.890

Participant 5

So with this different period, like a very clear different period and I think that so for me it's yeah. It's very much about like a change of identity and even though that is obviously painful in some level, but like obviously for me it's like you know part of growing up and you know getting older and becoming more mature is, you know your identity does change like you do you know hopefully grow in that sense and so, for me, like it's yeah like sort of looking back on my old self in that sense like it did it. There was a sort of a catharsis there, I think.

00:20:21.930 --> 00:20:25.540

Participant 5

And so even though yes like it, it was, uhm?

00:20:26.670 --> 00:20:44.170

Participant 5

Yeah, it was. There was like a sadness there, but then there was also like a sense of like progressing through these different stages and then you know, coming out in, you know I am a changed person. There is a positivity there and I think so in a weird way. It was nice to then go through that journey and then come out the positive end I suppose.

00:20:48.030 --> 00:20:55.050

Participant 2

I was I was thinking just in terms of how helpful it was to do this.

00:20:55.680 --> 00:21:22.240

Participant 2

In retrospect or how much it might have been a bit helpful along the way, and I didn't know the answer to that question, but I guess like in the spirit of everybody's been Marie Kondo'ing. I guess so, like with the things we've thrown away along the way also had a meaning to them or to the time that you throw certain things away so it I don't know. I don't know whether there's.

00:21:23.130 --> 00:21:26.030

Participant 2

This may be a value in some of this as a sort of.

00:21:26.650 --> 00:21:54.600

Participant 2

We all probably had all sorts of notebooks that we had to take two and from the hospital, but actually like something along the way. I don't know if I'd have had the brain space at the time, but whether as a sort of journaling tool as you go, but I. I also think there's only with the distance that I can notice some of those real shifts that other people have been talking about feeling more comfortable.

00:21:55.270 --> 00:21:57.170

Participant 2

..with what I wear and why I wear it?

00:22:00.130 --> 00:22:00.460

Rhian Solomon

Yeah.

00:22:00.640 --> 00:22:11.220

Participant 4

Yeah, it's helped me. I've used it as an opportunity to go through the wardrobe and I've got rid of some stuff that's just sort of been hanging around, reminding me of past times.

00:22:12.270 --> 00:22:15.560

Participant 4

That should have probably been on its way a long time ago.

00:22:16.630 --> 00:22:19.120

Participant 4

I feel better, I do feel better for it, to be honest.

00:22:20.480 --> 00:22:23.060

Participant 3

Yeah, I do too, it's been.

00:22:24.620 --> 00:22:36.430

Participant 3

I suppose difficult to do, but also I'm kind of really pleased that I've done it, and at the back of my mind there's always, if we can help somebody else along the way. That's so important.

00:22:37.950 --> 00:22:39.230

Participant 3

Yeah, I think it's just.

00:22:40.080 --> 00:22:52.110

Participant 3

I hope I've always kind of been really optimistic. I guess after my treatment and just always tried to bring that into my life and I just look at this as something positive to help others.

00:22:57.320 --> 00:23:06.840

Rhian Solomon

I'm wondering about how people found thinking about, you know, the second activity really got you to think about how

00:23:07.410 --> 00:23:12.500

Rhian Solomon

your wardrobe may have changed particularly..

00:23:13.420 --> 00:23:14.320

Rhian Solomon

the style, the cuts..

00:23:18.680 --> 00:23:28.970
Rhian Solomon
'I'm, I guess I'm asking you to think about your wardrobe in a way that you wouldn't necessarily think about clothes in particular or in a specific context.

00:23:30.040 --> 00:23:32.790
Rhian Solomon
I'm wondering how people found that process of..

00:23:33.510 --> 00:23:34.000
Rhian Solomon
Thinking

00:23:34.050 --> 00:23:43.220
Rhian Solomon
about how their wardrobe had physically changed. The colours. The cut as I said. What did people think about that process?

00:23:45.180 --> 00:23:46.750
Participant 4
I think I was drawn to.

00:23:50.100 --> 00:23:51.620
Participant 4
After I had a

00:23:52.440 --> 00:24:01.880
Participant 4
Reconstruction and a reduction. At the same time and the reconstruction was probably about two cup sizes bigger than the other one, so I was lopsided so.

00:24:02.920 --> 00:24:09.540
Participant 4
I found myself actually wearing sort of looser tops for a while, but usually patterns.

00:24:10.190 --> 00:24:17.770
Participant 4
As a distraction so that you don't. You don't notice that nothing very, very obviously baggier, but busier.

00:24:19.180 --> 00:24:21.610
Participant 4
Almost just like a camouflage.

00:24:23.600 --> 00:24:27.300
Participant 4
Which I don't think I'd consciously thought about, but that's obviously what.

00:24:29.880 --> 00:24:37.350
Participant 3
and I think as well when you look at the swatches, where we put the little colours. I can't believe I kind of.

00:24:38.190 --> 00:24:49.470
Participant 3
..how the spectrum of colour has changed to the final couple, or well the last three outfits in particular. There's just so much colour in my wardrobe now.

00:24:50.670 --> 00:24:52.010
Participant 3
So it's a nice thing.

00:24:54.640 --> 00:24:59.580
Participant 5
I was actually I had mixed feelings about this exercise because.

00:24:59.760 --> 00:25:05.820
Participant 5
you know the sort of before couple (items of clothing). Like there's some clothes which were like really colourful.

00:25:05.870 --> 00:25:27.060
Participant 5
Uhm and then as you look clearly it gets more monochrome and I think, like, now it's actually less colour and I was thinking like oh what does that mean? You know, 'cause clothes are like sort of psychically are

like more colour positive and then. But for me, even though I feel more positive now or about things, like my wardrobe is not reflecting that in a sense and I was like and I was trying to like.

00:25:27.700 --> 00:25:38.170

Participant 5

ask like what does that? Yeah, what does that actually mean? And I don't really know or have the answer, but I just, I don't know. I don't know whether anyone else has experienced this, but I think maybe I should talk to my therapist about that.

00:25:44.690 --> 00:25:57.920

Rhian Solomon

Does anyone else wanna add anything about how the colour changes? 'cause obviously colour can be connected to our mood, but there's also lots of other reasons why the colours might change within our wardrobes or how we may be actively using colour to kind of.

00:25:59.270 --> 00:26:11.000

Rhian Solomon

Make us feel a certain way potentially, but did everyone feel that actually the colours have changed or these different aspects of their wardrobes change? Or perhaps some people felt you know that.

00:26:11.750 --> 00:26:18.900

Rhian Solomon

These kind of physical elements of your garments, getting you to think about these changes..maybe you felt that there weren't changes.

00:26:19.530 --> 00:26:20.240

Rhian Solomon

Um.

00:26:21.380 --> 00:26:29.990

Participant 6

I certainly had brighter colours, that's for sure. But before I had my treatment before I had chemotherapy, I had long sort of blonder hair.

00:26:30.720 --> 00:26:42.410

Participant 6

And I made the choice, like once I've had my chemo and my hair went really really stubbly and short that I wouldn't dye it anymore. So my grey hair has actually made me look at other colours.

00:26:43.700 --> 00:26:54.390

Participant 6

to wear, but bright, it may be brighter colours just to kind of contrast from the, you know, the grey hair side of things. So yeah, I have. I've definitely gone for brighter things.

00:26:55.430 --> 00:27:06.550

Participant 6

I'm not always big..like not always, you know the whole outfit, but maybe the scarves and the accessories and things like that. Just add into the mix.

00:27:11.060 --> 00:27:12.370

Participant 2

I um.

00:27:13.520 --> 00:27:25.780

Participant 2

Hadn't really put my finger on it, but I found that I wore some things in the middle that I didn't know it, but I realize it now that that was 'cause they were. Also, colours that I didn't really love so the

00:27:26.480 --> 00:27:28.980

Participant 2

the zip up sports bras which.

00:27:29.810 --> 00:27:35.420

Participant 2

I never want to see again or in the colour, that I'm not particularly fond of and um.

00:27:36.190 --> 00:27:44.550

Participant 2

And actually, that's fine, because whatever I buy in the future, it won't look like that one. 'cause it will never be that colour. 'cause I don't like the colour. And I'm not buying one with a zip.

00:27:46.620 --> 00:27:49.730

Participant 2

Yeah, so that was a abit interesting so.

00:27:47.470 --> 00:27:47.770
Participant 6
Yeah.
00:27:50.900 --> 00:28:02.830
Rhian Solomon
There's something about colours that were available to you, you know, or a limited palette colours that were, hopefully, you know, the fashion industry could work on a little more.
00:27:56.310 --> 00:27:56.750
Participant 2
Yeah.
00:28:03.430 --> 00:28:04.750
Rhian Solomon
That could inform colour selections.
00:28:05.350 --> 00:28:11.810
Rhian Solomon
Was anyone actually actively adapting or changing their garments, you know?
00:28:11.870 --> 00:28:29.170
Rhian Solomon
Moving on to thinking about how you might have literally worked into a garment, whether you changed, I don't know, the structure of a garment or a neckline. Like you might choose a colour of a garment. Did anyone change their garments?
00:28:30.150 --> 00:28:33.040
Rhian Solomon
actively, in the group at all.
00:28:34.160 --> 00:28:43.100
Participant 6
I've changed one dress. I picked this particular dress out 'cause it was quite baggy and floating. It was, uh, a summer dress 'cause I'd had my surgery in July so I it was easy to wear.
00:28:43.720 --> 00:28:44.320
Participant 6
Uhm?
00:28:45.670 --> 00:29:13.240
Participant 6
And I've subsequently, I like it, but it was just way too baggy and just uncomfortable to be so baggy and it had slits up the side as well which were really kind of, I thought a bit too revealing. So, literally I've just completely remade it. I've literally taken the whole thing in and taken in the sides and everything, but I think that's the only item I've actually changed in any way. If I didn't like it, I probably got rid of it rather than actually adapt it, more likely, but that is distinctly. It's got such a significant.
00:29:14.290 --> 00:29:26.710
Participant 6
Reason for putting it in the mix. It's because it was the one I wore on the day to the hospital for the surgery on the 1st surgery that I just thought, that's gotta be in and it is one that I actually still wear and has been adapted so.
00:29:27.390 --> 00:29:29.190
Participant 6
So that's the only thing I think I've done.
00:29:32.520 --> 00:29:36.940
Rhian Solomon
Any other adaptations to garments?
00:29:40.400 --> 00:29:44.090
Rhian Solomon
Anyone adapting the garments based on?
00:29:46.620 --> 00:29:53.160
Rhian Solomon
Changing the way that you wear your garments so that might include things like I don't know. It might have particular.
00:29:53.800 --> 00:30:02.980
Rhian Solomon

ways that you layer clothing or wear freer clothing or different types of materials within clothing. Was anyone kind of..

00:30:03.840 --> 00:30:15.540

Rhian Solomon

conscious about those kinds of adaptations around how you thought about or how you changed how you wore your clothes across this period.

00:30:17.830 --> 00:30:22.530

Participant 2

I realize that I like the first Summer. I had worn..

00:30:23.240 --> 00:30:54.130

Participant 2

lots of vest tops underneath, shirts, so I think I just was really conscious about anything being see through or kind of accidentally showing some cleavage which would be quite shocking for people to see and realizing that now some of those same shirts were not even particularly see through. And now that I have a kind of good bra, I'm just comfortable to wear it as it is, so I hadn't.

00:30:54.490 --> 00:30:59.840

Participant 2

really registered that, but I guess there'd been these extra layers of

00:31:00.530 --> 00:31:02.830

Participant 2

Protection, I suppose, I've been.

00:31:03.550 --> 00:31:05.410

Participant 2

Wearing for a while.

00:31:07.480 --> 00:31:14.310

Rhian Solomon

I mean, how did you find them making those? Modifying thinking about those adaptations that you made?

00:31:16.240 --> 00:31:19.060

Rhian Solomon

To the way that you're wearing clothing.

00:31:21.590 --> 00:31:22.000

Rhian Solomon

Let's see.

00:31:21.600 --> 00:31:24.400

Participant 2

I guess I mean it just reminded me of, sort of.

00:31:25.490 --> 00:31:51.800

Participant 2

After having various bits of the reconstruction like, you end up back in the space of having bits of foam in your bra or pads on again. So, I guess in some ways it isn't a problem, it's just like 'Oh well', after I've had that done, then I go back to this, but in a few weeks time we'll be back to normal again. So I think it's it. Just it feels very medical to be honest. This is, this is the bra that I wear if I have.

00:31:52.900 --> 00:31:54.240

Participant 2

more dressings.

00:31:55.850 --> 00:32:07.820

Participant 2

And yeah, I dunno, I suppose maybe that's quite healthy, isn't it? It didn't send me into a flat spin. It was just oh right, this is the, this is the surgical kit.

00:32:12.060 --> 00:32:31.810

Rhian Solomon

Part of the journey? Definitely it's like. I'm wondering how people found thinking about their future wardrobes 'cause a big part of the activity packs is obviously reflecting on your wardrobes to this point. But it might feel a little bit abstract thinking about what your future wardrobe entails, but I'm wondering how people.

00:32:14.270 --> 00:32:14.570

Participant 6

Yes.

00:32:32.510 --> 00:32:34.800
Rhian Solomon
found that process.

00:32:38.580 --> 00:32:43.590
Participant 3
I think it depends also on if you need future surgery.

00:32:44.360 --> 00:32:47.220
Participant 3
Like for me, I've got an implant that.

00:32:47.980 --> 00:33:06.130
Participant 3
I had an implant that went hard so they took that out, gave me more symmetry at the same time so that changed things slightly again with my wardrobe, but now the implant I've got feels fine, but it's been taken off the market, so although it doesn't have to be removed now, it does need to be at some point.

00:33:06.640 --> 00:33:19.650
Participant 3
Uhm, [REDACTED] Hospital have said they'd see if they could use it, but because there's litigation in America, we can't. So for me, it's always like Oh well, what shape will I be after the next surgery? Because.

00:33:20.300 --> 00:33:21.090
Participant 3
After

00:33:22.030 --> 00:33:38.710
Participant 3
the last implants, this implant I was a different shape because the implant is a different shape. So I think that also alters how you think how you might wear something, because suddenly something you've thought fitted you can look quite different with a different bra and a different sized chest.

00:33:39.760 --> 00:33:46.100
Participant 3
So yeah, so I don't think there's a definitive answer on what you think your future wardrobe will be like, because it will evolve.

00:33:46.730 --> 00:33:53.610
Participant 3
If you have to have an implant removed and now I have the prosthesis again.

00:33:54.460 --> 00:33:59.020
Participant 3
This is amazing, just in the last few days. The difference, I feel.

00:33:59.870 --> 00:34:03.700
Participant 3
Going back to a proper mastectomy bra with this in it is.

00:34:04.370 --> 00:34:12.610
Participant 3
It's just been really, really nice and I wouldn't have done this if it wasn't for you and the study. It was just something I knew.

00:34:13.670 --> 00:34:38.930
Participant 3
Maybe I could do, but I don't know. I, was just sitting there one day...I just thought, well I'll go on the Nicola Jane website and just see and then it was a fluke that this woman happened to be the fitter for London. Happened to be so close to where I live. And yeah I'm just so so pleased I've done it. So again that's giving me confidence, maybe to wear something that even two weeks ago I wouldn't have worn so.

00:34:41.390 --> 00:34:42.390
Rhian Solomon
It's really nice to hear. Thankyou

00:34:43.290 --> 00:34:51.180
Participant 3
No, Thank you. 'cause it's something that's so positive that's come out of it for me, which is great.

00:34:53.340 --> 00:35:03.570
Rhian Solomon

it does lead me quite nicely into the next question, which is, have these activities helped you to reflect on your experiences of breast cancer in different ways?

00:35:04.340 --> 00:35:05.320

Rhian Solomon

How do people feel..

00:35:06.080 --> 00:35:12.980

Rhian Solomon

now, having done, I know it's quite a compressed, period of time that you've worked on these packs.

00:35:13.930 --> 00:35:15.520

Rhian Solomon

Three to four weeks.

00:35:16.090 --> 00:35:20.080

Rhian Solomon

Has it helped you to reflect in a different way?

00:35:20.780 --> 00:35:21.450

Rhian Solomon

Um

00:35:23.170 --> 00:35:30.980

Participant 4

I think for me, the activity with the collage. When I looked at the back and my view of the journey, it was very much.

00:35:33.460 --> 00:35:35.760

Participant 4

Sort of a straight up, I know I'm.

00:35:36.610 --> 00:35:53.250

Participant 4

Everything was explained to me that it may not be straightforward and there may be many stages and revisions, but I think, in sort of self-preservation mode, I didn't let myself consider anything other than it's going to be this to this and will be over within a year.

00:36:07.860 --> 00:36:08.640

Participant 4

So that was.

00:36:09.920 --> 00:36:11.280

Participant 4

Interesting and also.

00:36:12.820 --> 00:36:19.880

Participant 4

Thinking about myself then and how I presented myself um, I was very sort of.

00:36:21.090 --> 00:36:23.150

Participant 4

Closed off..presenting UM.

00:36:24.380 --> 00:36:31.910

Participant 4

a very controlled view. Everything was very. I've put a jar on there (on the collage). The jar of emotions and everything is sort of crammed in the jar.

00:36:32.810 --> 00:36:46.300

Participant 4

Um, not really being sort of looked at and explored, but there's bits sort of eeking out, but there's a great big question mark in the middle. A big black question mark, which is everything..at the centre of everything there's this big, question mark? And then.

00:36:47.170 --> 00:36:53.340

Participant 4

On the, on the front the question mark's abit smaller, pushed aside but.

00:36:54.180 --> 00:37:05.080

Participant 4

The journey is still there, but the journey instead of being on a clear background is on a collage of loads of different colours and textures, and there's all of this other stuff going on up here, which is the backdrop of life.

00:37:06.010 --> 00:37:16.310

Participant 4

Which is actually how the reality of this. That it's not just going on in isolation. It's going on against everything else that's happening, you know.

00:37:17.650 --> 00:37:20.850

Participant 4

People changing jobs. We have things happening with family members.

00:37:21.600 --> 00:37:22.000

Participant 4

Uh.

00:37:23.190 --> 00:37:26.730

Participant 4

Everything else comes into, comes into play, so yeah, I think it was.

00:37:28.010 --> 00:37:32.690

Participant 4

A really helpful way to sort of question why.

00:37:35.070 --> 00:37:39.560

Participant 4

Yeah, why I did sort of mask my emotions and didn't really...

00:37:40.270 --> 00:37:41.000

Participant 4

Open up.

00:37:41.650 --> 00:37:42.860

Participant 4

Why that might be?

00:37:43.910 --> 00:37:44.520

Participant 4

Uhm?

00:37:45.130 --> 00:37:45.680

Participant 4

But yeah.

00:37:47.540 --> 00:37:59.870

Participant 6

I think for me, I've basically probably realized that I've been Mrs Angry up to now about the whole thing, and actually going through this whole process has made me feel a lot more appreciative of where I'm actually at.

00:38:01.780 --> 00:38:28.840

Participant 6

Yeah, 'cause I was always looking back and it would just rile me up and just make me feel really cross but it's actually made me feel a lot more appreciative of where I am now actually and how far I have come. You know treatment was forever. It seemed like forever and then obviously I'm kind of two years on from the end of that now. And it's, I think, I've still been quite angry but actually having to physically create something that's actually got some of that.

00:38:29.990 --> 00:38:34.630

Participant 6

Anger out UM down on the bit paper, which I think is quite good.

00:38:35.720 --> 00:38:54.000

Participant 6

That's freed me up a little bit to be a bit more positive. I don't think I've been that positive about the whole thing really, but it's made me feel a bit more positive about everything and that I'm going in the right direction and that things will be brighter and better for me in the future. Yeah, 'cause I've been in a bit kind of dark places I think.

00:38:55.550 --> 00:38:57.940

Participant 6

Yeah, so that's been quite positive on that respect.

00:39:00.610 --> 00:39:09.720

Participant 2

I found it really cathartic, the T-shirt exercise and that collage that.

00:39:00.670 --> 00:39:00.960

Participant 5

I think.

00:39:10.840 --> 00:39:41.050

Participant 2

Um, it gave me an outlet that maybe feedback forms at hospitals didn't give me of saying some things and, I guess, there's for me..I kind of felt a bit in the vibe of that it was graffiti or it was kind of a protest. And that was so helpful to just write some things down when you don't have to be deeply grateful to the person who spent nine hours of his life sewing you back together.

00:39:41.410 --> 00:39:44.640

Participant 2

Like it, it was an OK place to say some things that you.

00:39:45.440 --> 00:39:54.020

Participant 2

That I wanted, I found I wanted to say and so I really. I didn't know I needed that exercise but I.

00:39:54.630 --> 00:39:58.090

Participant 2

Really needed that exercise and in the framing of.

00:39:58.920 --> 00:40:03.840

Participant 2

the question asked of what, what do you? What do you want professionals to know?

00:40:04.520 --> 00:40:09.670

Participant 2

That was powerful, so yes. So thank you, yeah.

00:40:12.660 --> 00:40:13.030

Participant 6

Yeah.

00:40:14.090 --> 00:40:18.080

Participant 5

Yeah, I think for me, 'cause I I've finished my.

00:40:18.780 --> 00:40:32.230

Participant 5

chemotherapy treatment a few months ago and so I think it's like so I've not..It's still quite fresh for me I guess like this whole experience and then I was thinking back to yeah when we got to the T shirt exercise how?

00:40:32.850 --> 00:41:03.060

Participant 5

Uhm, like yeah obviously I was having my intravenous chemo and then you know they put you in for surgery and it's all happening very fast and you know. And I think at the time it was just like, oh you know, just yeah, just get through it, crack on with the next thing, you know, trying to be brave etc and, you know, that's like your MODIS operandi in that time and you just sort of, everything is just kind of trickling along. And so, I think I realized that I had not actually had that much time to process like how I actually really felt about this surgery, if that makes sense. It's like it.

00:41:03.270 --> 00:41:03.980

Participant 5

And so.

00:41:05.910 --> 00:41:37.370

Participant 5

Then doing yeah, doing the college exercise like it took me a really long time to actually do the first part because I just really just sat there. Like having to like peel away the layers. I guess that I'd sort of probably put up against how I was feeling at that time, 'cause I didn't want to. You know, to be scared or to, you know, feel you know, feel, feel sad about it, almost like it was, you know, I just wanted to just get it done. You know, get it out of the way and so yeah, when I actually did do the college. I was actually surprised like how.

00:41:37.610 --> 00:41:42.770

Participant 5

It's quite like, I mean, when you see it. I guess when you get it, it looks a bit sort of like a horror film.

00:41:43.540 --> 00:41:58.820

Participant 5

You know it's very like, it's quite dark and yeah, and it's sort of very surgical and a lot of blood. And all this kind of stuff and I and I was like and I was actually surprised I was like, oh God, yeah, I guess I had. I had a lot of feelings about this and I didn't even, I wasn't even processing it at the time.

00:41:59.880 --> 00:42:06.320

Participant 5

So yeah, so you ultimately, as Participant 6 was saying it's like it is, it is.

00:42:07.400 --> 00:42:27.320

Participant 5

Ultimately, it's come out as a positive thing because you know, I was obviously feeling very, very... I didn't realize like how dark I was feeling about that, and then I think now I can kind of reflect back on that which you know. And again, yeah, thank you to you Rhian for obviously allowing that process to happen and to have that kind of catharsis.

00:42:29.710 --> 00:42:35.170

Rhian Solomon

So, I'm hearing the making, from a lot of you..this process of making has really.

00:42:35.720 --> 00:42:40.020

Rhian Solomon

Has been a deep reflective process that's allowed you to think about.

00:42:40.070 --> 00:42:43.200

Rhian Solomon

Or reflect on your experiences in.

00:42:44.800 --> 00:42:49.190

Rhian Solomon

In other ways that you didn't necessarily expect.

00:42:51.570 --> 00:43:19.750

Rhian Solomon

Would you say that the making, particularly 'cause I'd say that some of the activities were more, I guess documentary and that you're documenting how you guys are changing, but the other activities which were like the collage and the T shirts, particularly are much more expressive and much more hands on as well, you know, like actually getting your hands in there with the materials and selecting those materials as well. It seems like those.

00:43:20.690 --> 00:43:23.960

Rhian Solomon

Activities from some of the things that you have said were.

00:43:27.260 --> 00:43:33.170

Rhian Solomon

were helpful, were useful..just kind of reflecting in a different way potentially.

00:43:35.020 --> 00:43:37.090

Rhian Solomon

Is that right?

00:43:38.510 --> 00:43:39.030

Participant 3

Yeah.

00:43:39.950 --> 00:43:43.220

Participant 3

I think with the T shirt, as well, I'm, I don't know like when I.

00:43:44.330 --> 00:43:48.260

Participant 3

sort of sat there first thinking what have I got to say?

00:43:49.040 --> 00:43:59.810

Participant 3

And then all of a sudden it was like OK. I'm just writing. It's just coming. It's just coming and coming and coming and and..And I don't know. Maybe because of where I am now.

00:43:59.860 --> 00:44:17.080

Participant 3

And because, you know, everyone sort of says 'oh you're always so positive you always stay positive and I am. But it's because I don't share the darker thoughts. It's not that I have dark thoughts all the time but there are some there and I don't share those with people so.

00:44:17.130 --> 00:44:27.440
Participant 3
So, I think, if I have a time where I feel a bit strange or a bit reflective, it's almost like, oh is she alright.
00:44:17.430 --> 00:44:17.820
Participant 4
Uh.
00:44:28.230 --> 00:44:32.270
Participant 3
I don't know. I think you have like this period of time where it's almost.
00:44:33.150 --> 00:44:35.080
Participant 3
Acceptable to talk about it.
00:44:35.730 --> 00:44:39.110
Participant 3
But then you have to just get on with life so.
00:44:39.960 --> 00:44:44.850
Participant 3
For me, now, it's like I'm not gonna sit down and have a conversation.
00:44:45.670 --> 00:44:57.830
Participant 3
Five years later about how I feel because I'm aware of it every day. I see it in myself. Every day I look at myself. I can see that I have an implant. Um but it's.
00:44:58.420 --> 00:45:04.500
Participant 3
That's something for me to deal with now. It's not to have conversations about with others, so this is giving me an opportunity.
00:45:05.380 --> 00:45:22.120
Participant 3
In good and bad but more good than bad to actually really think about how I feel and I think in the bigger picture. It's all been really positive. It's been very tiring. Like Participant 6 said, I have been really tired.
00:45:22.730 --> 00:45:30.160
Participant 3
And that was. I wasn't expecting that to feel very drained after doing it.
00:45:31.110 --> 00:45:42.290
Participant 3
The way you'd written 'have a cup of tea' or 'see a friend', or you know. It isn't necessarily that I did that but I totally appreciated why you've put that, because I think we kind of did need.
00:45:43.140 --> 00:45:46.220
Participant 3
Little breaks, it's OK to feel sad, as well.
00:45:50.500 --> 00:46:08.370
Rhian Solomon
So, you think it's, you know, provided not just a kind of practical means, but also literally provided space. You know it's a process of slowing down or taking the time out. Allocate potentially.
00:45:58.400 --> 00:45:58.880
Participant 3
Yeah
00:46:05.370 --> 00:46:06.060
Participant 3
Yeah.
00:46:08.960 --> 00:46:12.040
Participant 3
Yeah, I, I think so. When I..
00:46:13.000 --> 00:46:36.230
Participant 3
First had my first biopsy. My mum became unwell. She had a fall and she wasn't quite well and then by the time I had by mastectomy my mum was showing early signs of dementia. So, in my head, I don't know why, I decided that my mum becoming unwell was because she was worried about me.

00:46:37.050 --> 00:46:51.220

Participant 3

And I had this really weird thought process which was now, in hindsight, was ridiculous. But at the time I was like, Oh my God, my mom is really worried about me and I'm making her unwell. Well, which of course wasn't the case, but.

00:46:52.020 --> 00:46:55.410

Participant 3

I think it's funny how your anxiety.

00:46:56.020 --> 00:46:57.520

Participant 3

Can come out. Rather than,

00:46:58.350 --> 00:47:02.770

Participant 3

I don't know about the rest of you, but it took me a really long time to say that I had cancer, it was like.

00:47:03.670 --> 00:47:07.610

Participant 3

Oh well, I've just gotta have this surgery 'cause I've got this thing and then I'll be fine.

00:47:08.570 --> 00:47:12.790

Participant 3

But, I didn't actually want to say, yeah, I, I've got cancer.

00:47:13.770 --> 00:47:14.250

Participant 3

That was.

00:47:15.500 --> 00:47:17.680

Participant 3

So yeah, I think I. I kinda pushed it

00:47:18.330 --> 00:47:20.110

Participant 3

..on other thoughts.

00:47:21.080 --> 00:47:48.210

Participant 6

I think what happened to me. I did tell everybody when I had cancer and then I realized this time, when I had to go to this biopsy..I decided to tell absolutely nobody 'cause I just thought, well, it probably, as I say, it turned out to be nothing but I just thought I can't. I always felt like I can't do this to you again. I can't put you, my family and my daughter and I just, so I didn't tell. Literally, I think, the one person I told, was another breast patient that I've met along the way that..

00:47:48.270 --> 00:47:54.180

Participant 6

was the person I told. But yeah, 'cause I just felt God I can't go through this again. You know what I mean? And, I do feel.

00:47:55.490 --> 00:48:01.770

Participant 6

I can't..with friends and things...I think I've kind of said everything I can say about.

00:48:02.940 --> 00:48:15.560

Participant 6

The process and going through everything and I think you know I don't want to tire them out with my thoughts and any dark thoughts. When you're going through anything in the future. Do you know what I mean I just. I think I'm kind of done with it.

00:48:13.840 --> 00:48:14.260

Participant 3

Yeah.

00:48:17.270 --> 00:48:17.640

Participant 6

So.

00:48:17.350 --> 00:48:20.200

Participant 4

I think just people just don't know what to say.

00:48:21.040 --> 00:48:25.570
Participant 4
There's anxieties but they..

00:48:21.220 --> 00:48:21.840
Participant 3
Yeah.

00:48:26.180 --> 00:48:26.580
Participant 6
Yeah.

00:48:26.420 --> 00:48:26.840
Participant 4
Yeah.

00:48:27.610 --> 00:48:28.380
Participant 4
They don't wanna go there.

00:48:28.430 --> 00:48:28.630
Participant 4
Yeah.

00:48:29.020 --> 00:48:29.350
Participant 6
Yeah.

00:48:29.800 --> 00:48:31.100
Participant 3
Yeah, I agree.

00:48:31.260 --> 00:48:34.590
Participant 6
Well, yeah, you're right, they don't know what to say anymore. That's the thing, yeah.

00:48:34.320 --> 00:48:34.540
Participant 4
So..

00:48:35.880 --> 00:48:53.400
Rhian Solomon
Just, so just building on..I'm wondering..you talked about Participant 3 the pack being a space for you to understand, and reflect in a personal, safe, safe way. But I'm wondering whether there is a life beyond.

00:48:35.930 --> 00:48:36.350
Participant 3
Yeah.

00:48:54.640 --> 00:49:01.440
Rhian Solomon
This stage of working on the pack where you might use it.

00:49:02.610 --> 00:49:06.740
Rhian Solomon
Or things that you've created from the pack? I'm wondering whether.

00:49:07.650 --> 00:49:17.120
Rhian Solomon
There's a space for it being used in other places or to talk with other people about your experiences, or whether you feel that it's more.

00:49:18.400 --> 00:49:26.060
Rhian Solomon
of a personal thing I don't know if there is..I guess a life beyond the activities that we've done today.

00:49:26.120 --> 00:49:32.480
Rhian Solomon
Or maybe the artifacts that you've created. Is this something that anyone has thought about at all.

00:49:34.650 --> 00:49:35.320
Participant 3
Well, I think.

00:49:37.230 --> 00:49:55.090
Participant 3

meeting the lady I met this week, who does all the fittings for the prosthesis. So, it's just hearing her story. What a positive woman she is in her mid 50s. She found her first lump.

00:49:55.750 --> 00:50:16.490

Participant 3

in her breast in her 20s so suddenly her life became about realizing 'hang on a minute' there aren't bras that are acceptable for me to wear, and so it's just listening to other people and thinking. Actually, what can I do to help. Now I feel so comfortable that I want to help other people.

00:50:17.200 --> 00:50:21.270

Participant 3

But doing it in a controlled manner, I think for me.

00:50:22.240 --> 00:50:32.010

Participant 3

When somebody asks you questions, but they're not asking them in the right way, or they're maybe not qualified to ask the questions.

00:50:32.660 --> 00:50:39.050

Participant 3

And that's what I want to avoid. I think, like, if you go for a bra fitting, for instance, I,

00:50:40.020 --> 00:50:44.880

Participant 3

after my mastectomy, I had a bra fitting and it was amazing. And then after my,

00:50:45.940 --> 00:50:56.070

Participant 3

Second major surgery where I had to get more bras, new bras, and the girl wasn't fitting me properly and I..

00:50:57.150 --> 00:51:22.000

Participant 3

I was okay, I was in the changing room? But I could hear her. She brought me a bra that didn't fit me. I knew it wasn't gonna fit me and I said look that won't fit me. She said 'it will, it's your size. I've measured you'. And I said actually it won't. And I explained when I booked the appointment I'd had a mastectomy and then I could hear her outside saying 'Oh my God that woman in there, she's so fussy. Nothing is gonna fit her, is it?'

00:51:19.500 --> 00:51:19.960

Participant 5

Yeah.

00:51:22.700 --> 00:51:35.180

Participant 3

And I just thought, well, this isn't gonna fit me. So I took the bra and I just walked back out and I said excuse me, I've booked a mastectomy fitting for a reason. It's not going to fit me but you haven't made me feel great.

00:51:36.000 --> 00:51:37.160

Participant 3

And I left the shop.

00:51:37.920 --> 00:51:38.660

Participant 3

And I think.

00:51:40.070 --> 00:51:43.220

Participant 3

The reason I've signed up to what you're doing.

00:51:43.880 --> 00:51:52.330

Participant 3

It's just you want people's understanding that it is different. You are different. An implant feels

00:51:53.300 --> 00:52:05.840

Participant 3

Very unlike a real breast and all you want is that when you go somewhere, just that care and attention to realize that you are not wearing a normal bra. But even if you are wearing a normal bra.

00:52:06.440 --> 00:52:10.740

Participant 3

You're approaching it differently to before you had surgery.

00:52:11.690 --> 00:52:12.370

Participant 3

So..

00:52:13.540 --> 00:52:14.340

Participant 3

Yeah, yeah.

00:52:15.220 --> 00:52:17.360

Participant 3

I guess what am I trying to say. You just.

00:52:18.170 --> 00:52:34.000

Participant 3

You want people to have knowledge like whatever you learn from us as a group of women that going forward can help someone else to go in somewhere and feel confident that you're taking your bra off.

You're exposing your scarring. Whatever else you've got.

00:52:34.850 --> 00:52:36.890

Participant 3

You don't want to feel like you're the little.

00:52:39.080 --> 00:52:53.190

Participant 3

Like there's something wrong with you. There's nothing wrong with us. We're very fortunate people.

We've had treatment and we've come out the other side of it and we are very, very lucky and I want to celebrate that, not feel embarrassed that I'm going somewhere because I'm different.

00:52:57.160 --> 00:53:16.640

Rhian Solomon

So, it's a way of communicating your experience to other people, potentially the outcomes of the project. And this might be something that comes forwards in the workshop that we run as well. When we will actually be together and able to, you know actually talk about some of these experiences.

00:53:17.660 --> 00:53:18.500

Rhian Solomon

But that you..

00:53:18.080 --> 00:53:45.040

Participant 2

Sorry, can I add a story, so I think I'm now realizing I wouldn't have done it if I hadn't signed up for this workshop but um yes. So I bought a new running bra and, UM, I bought it online and I needed three different ones until they found the one that fitted and I decided to write a thank you letter to that sports shop saying.

00:53:45.690 --> 00:54:15.450

Participant 2

Thank you, you have no idea what this means to me that you let me, for no cost, return two bras to find the one that I'm happy with. You might not realize this but there'll be other women like me and keep your returns policy and I don't think I'd have had the courage to do it, but I think it's finding those places where this made me realize it's OK to say that clothes matter and and that things like a returns.

00:54:15.730 --> 00:54:25.960

Participant 2

Policy for a running shop can make someone feel comfortable and standing there in the changing room in the shop.

00:54:26.790 --> 00:54:40.930

Participant 2

Tying to fit into one of the ones that they have in the shop wouldn't make me feel comfortable, so yes. So thank you. I hadn't quite realized that this project had shifted something and choosing to be, I suppose an advocate in.

00:54:41.590 --> 00:54:43.260

Participant 2

One place so far, so.

00:54:46.350 --> 00:54:48.110

Rhian Solomon

I mean I, I'm wondering.

00:54:48.460 --> 00:55:03.750

Rhian Solomon

whether you guys feel that there's benefits, particularly of working with clothing. You've just touched on that Participant 3. But do you think clothing in particular is useful?
00:55:04.780 --> 00:55:07.680
Rhian Solomon
I don't know whether tool is the right word, but, a, useful..
00:55:09.290 --> 00:55:17.610
Rhian Solomon
item, the things that we wear to talk about our experiences of breast cancer. Do you think clothing particularly is useful?
00:55:24.160 --> 00:55:25.150
Participant 3
It depends what.
00:55:26.430 --> 00:55:30.280
Participant 3
what item of clothing you're thinking about, really.
00:55:31.410 --> 00:55:38.700
Participant 3
Like a bra is probably the most important item of clothing, really because.
00:55:39.490 --> 00:55:41.790
Participant 3
If you feel comfortable in that.
00:55:43.570 --> 00:55:50.010
Participant 3
Yeah, so for me, probably bras are the hardest thing to buy and one of the most important.
00:55:55.920 --> 00:56:01.380
Participant 4
Yeah, since I've had my operation in the summer. I've gone back to wearing the bras..
00:56:02.000 --> 00:56:06.420
Participant 4
that I used, before all of this started and I actually feel more like me.
00:56:07.580 --> 00:56:09.160
Participant 4
Whereas, when I was wearing the..
00:56:10.400 --> 00:56:24.820
Participant 4
I did have mastectomy/post-surgery bras with pockets. That I just didn't get around to changing because I didn't see the point 'cause I was waiting for another operation. I thought well you need more bras and I hate them all anyway so.
00:56:25.490 --> 00:56:29.340
Participant 4
I'll just put a T-shirt over the top and forget about it, but.
00:56:30.360 --> 00:56:40.320
Participant 4
The way it makes you feel and the way it makes your clothes hang. And I just feel.. I went. I went for my first ever proper bra fitting in Bravissimo and it was just wonderful.
00:56:41.470 --> 00:56:41.880
Participant 4
Uh.
00:56:43.000 --> 00:56:50.020
Participant 4
Yeah, I think it does make a huge difference, so it's right at the centre of how you feel about yourself.
00:56:52.520 --> 00:56:54.410
Participant 4
And that's the most important thing really.
00:56:59.090 --> 00:57:02.910
Participant 5
Actually, I feel like with the clothes as well. Like, I think it is a really fruitful.
00:57:03.570 --> 00:57:12.300
Participant 5

vehicle to talk about these things, 'cause it's like clothes.. they're almost like a photograph aren't they. They just sort of..They bring back memories in a way that..

00:57:13.640 --> 00:57:24.070

Participant 5

And maybe then also 'cause it's like the smell dimension as well. Like I don't know if, you know like, it's kind of obviously the smell of something, like, even though it doesn't smell of anything in particular, but there's just something there that kind of brings back a memory or.

00:57:25.300 --> 00:57:41.190

Participant 5

I can't say I couldn't say that maybe the touch necessarily. I don't think I had that..I personally didn't have that kind of connection. It was more about smells and the like. Yeah, like a little Polaroid of a time or of some moments or some kind of emotion that I had so.

00:57:41.810 --> 00:57:43.810

Participant 5

That I didn't expect to. Yeah, I think, I think that.

00:57:44.760 --> 00:57:49.350

Participant 5

I think that yeah, like each garment tells a story I guess, so yeah.

00:57:52.980 --> 00:57:53.460

Rhian Solomon

So that.

00:57:53.090 --> 00:57:59.900

Participant 4

When I was in hospital, at ██████████ Hospital they were doing a fundraiser, UM, for the plastics unit for reconstruction.

00:58:00.830 --> 00:58:03.920

Participant 4

And they had a little video on there where.

00:58:04.660 --> 00:58:14.880

Participant 4

It was talking about, you know, the bras that women wear. You will remember your first bra, the bra you wore for your wedding..You know.. Your going out bra.

00:58:14.940 --> 00:58:23.600

Participant 4

Yeah, and it's something that's all through your life, your adult life, and it's probably the most significant item.

00:58:23.910 --> 00:58:24.420

Participant 6

Yeah.

00:58:24.610 --> 00:58:26.280

Participant 4

As a woman, isn't it really?

00:58:26.590 --> 00:58:26.940

Participant 3

In

00:58:27.570 --> 00:58:58.910

Participant 6

Well, I did think when I started the project, so I did look through my bra drawer. I could have done a history of my bra because I think I've got every single one, including all the zip up ones and all the post-surgery ones. And I almost thought about just laying them all out on the bed from start to finish and all that. But I've probably got more than 9, but I'm still thinking of doing that actually and just taking a photograph of them, not specifically for this project, but it would be quite interesting just to see them all. I think. And then I think I might just then go right 'You're going now' because they're hogging way too much space but.

00:58:59.290 --> 00:59:05.950

Participant 6

Yeah, I think I could have done that. I could have done my 9 items just in bras, I think, pre and post.

00:59:11.050 --> 00:59:18.280

Rhian Solomon

Does anyone feel like there's other types of items that would be useful to kind of reflect on your experiences?

00:59:19.040 --> 00:59:24.330

Rhian Solomon

Uhm, we've obviously centred around clothing quite specifically for the..

00:59:25.500 --> 00:59:28.030

Rhian Solomon

the activity pack but are there.

00:59:28.860 --> 00:59:38.980

Rhian Solomon

other types of objects or artifacts that you think would be useful to reflect on and talk about your experiences. Or do you think that clothing is?

00:59:39.870 --> 00:59:40.870

Rhian Solomon

Is more relevant.

00:59:42.290 --> 00:59:43.560

Rhian Solomon

Or useful, let's say.

00:59:45.480 --> 00:59:49.400

Participant 4

One thing I thought about was the drain and drain bag.

00:59:50.750 --> 00:59:52.220

Participant 4

What, you'd say to yourself.

00:59:52.890 --> 00:59:55.770

Participant 4

If you could go back in time, what you'd say to yourself then?

00:59:56.370 --> 00:59:59.350

Participant 4

What you need to know at this point. 'I'll be OK'.

00:59:59.980 --> 01:00:03.520

Participant 4

'It's horrible now. It's horrible, but it'll be OK in the future'.

01:00:07.600 --> 01:00:10.560

Participant 4

Yeah, all of those. All of those sorts of things. The bit if

01:00:11.740 --> 01:00:16.920

Participant 4

If you could tell yourself back then what you've learned along the way in some fashion.

01:00:18.920 --> 01:00:34.650

Participant 6

I think that was one of the things I put on the front of my T shirt is what I would have liked to have done when I was choosing my surgery or speaking to people that had the same type of Breast cancer as me. I would have liked to have met more people..

01:00:35.460 --> 01:00:40.970

Participant 6

..before I decided what I wanted to do, but I didn't get to meet anybody that had the surgery.

01:00:41.600 --> 01:00:42.480

Participant 6

that I had.

01:00:43.550 --> 01:00:46.190

Participant 6

Prior to, I don't even know if that's a thing.

01:00:46.920 --> 01:00:55.890

Participant 6

That they would even think of doing you know? 'Oh would you like to meet a couple of people that actually had that.' And you go 'yeah, I would actually', but there isn't that sort of device within the system to.

01:00:52.660 --> 01:00:52.990

Participant 5

Well.

01:00:56.720 --> 01:01:00.590

Participant 6

I mean I had triple negative breast cancer, so that's a reduced pool of people anyway.

01:01:00.640 --> 01:01:02.550

Participant 6

Uhm, I suppose.

01:01:04.280 --> 01:01:25.850

Participant 6

And then, as I say, I was given 7 days to decide what kind of surgery I was gonna have, anyway, 'cause I didn't have a complete response to the chemotherapy, so I was just gonna have a lumpectomy to start with. And then you're kind of faced with this, like well 'you can have a DIEP flap. You can have a mastectomy with an implant. You know, um, you can just have a lumpectomy. Or we can do this other thing called a mammoplasty.' I'm like..uh

01:01:25.920 --> 01:01:28.500

Participant 6

Because we need to know by next week.

01:01:28.560 --> 01:01:28.900

Participant 6

My god it's just like..

01:01:29.980 --> 01:01:37.980

Participant 6

You know, and it would have been helpful. I think you know, like we're saying we want this exercise to be helpful to others. I would love to be able to do that now for other people.

01:01:38.840 --> 01:01:42.780

Participant 6

To be able to sit with them and just say, well, these are the things that you might want to consider or.

01:01:43.520 --> 01:02:02.650

Participant 6

But there doesn't seem to be that ability in the system to be able to do that. I find it. They're actually quite negative actually within the system, they don't necessarily want patients..I think to actually..maybe in other environments, like say Maggie's or somewhere, like, they potentially would, but I find the hospitals don't particularly.

01:02:03.780 --> 01:02:13.390

Participant 6

have that device or certainly haven't had it recently, put it that way. I suppose because of COVID and all of that kind of thing. It hasn't helped at all in that respect.

01:02:14.030 --> 01:02:17.250

Participant 6

Uh, but even in the breast groups they don't particularly like you.

01:02:18.180 --> 01:02:20.810

Participant 6

Discussing too much, really, it seems to me.

01:02:21.730 --> 01:02:42.750

Participant 6

When people came up to me and asked me lots of questions, after the breast group like, well, you mentioned that in the breast group, can we just talk to you about that now, like, away from the psychologist and the breast nurse over there? We want to talk to you about those things but, but I think it's a much more open conversation that people would like to... I certainly would have liked to have had that myself or the opportunity to discuss that with other people.

01:02:43.620 --> 01:03:03.950

Participant 6

But I don't think hospitals like to do that. I think they think you might say something maybe uncomfortable or you say something that they don't believe is correct, or anyway that's just me having my moan. Sorry, I think that's where this creative thing comes in, as that would be a good device for people, maybe who've.

01:02:58.140 --> 01:02:58.510

Rhian Solomon

I'm not.

01:03:05.050 --> 01:03:10.510

Participant 6

You know, come to that point for them to maybe be offered that kind of exercise.

01:03:11.080 --> 01:03:14.450

Participant 6

For them to experience that for themselves.

01:03:15.220 --> 01:03:15.930

Participant 6

Um.

01:03:16.470 --> 01:03:19.590

Rhian Solomon

And this is exactly sorry. So, are you...

01:03:19.170 --> 01:03:44.970

Participant 6

So I'm sorry, I'm just having a little moment now 'cause I've found that so.., so I've done that kind of thing before at █████ Hospital where they had a little creative group. They tried to do something in their research department and it was, but it was only very few people and they never kind of developed it or moved on or got other people to do it more. I suppose, maybe that's again, 'cause of the COVID thing, but I think it would be good if that was kind of built into the system somehow, that as part of the cancer process you get to actually.

01:03:45.670 --> 01:04:07.200

Participant 6

Because I think a lot of people do have a kind of PTSD at the end of it all, because I know I did, I would sort of get through the end of it. 'cause as you said before, you work all your way through like nine months of treatment and you're just getting to the next thing. And the next thing. And the next thing. And then you sit back and reflect on it and think 'Oh my God'. And at that point I think, what would be so helpful is if people just said, well, we've got these sort of workshop things where you can come along and do a bit of creative.

01:04:00.740 --> 01:04:01.250

Participant 5

Uh.

01:04:08.440 --> 01:04:13.380

Participant 6

You know, maybe that would help people, so they wouldn't just go away and feel sort of isolated.

01:04:15.100 --> 01:04:18.680

Participant 6

Anyway, that's my thoughts. Sorry to go off.

01:04:18.160 --> 01:04:18.500

Participant 4

But

01:04:18.290 --> 01:04:18.700

Participant 3

Where?

01:04:19.390 --> 01:04:48.920

Participant 3

Just to say, where I had my surgery. There was a support group. One of the nurses very kindly did it and they had a charity fashion show. So, one of the shopping centres was in Brent Cross shopping centre. There was a shop that had beautiful dresses, evening dresses and things and they allowed us to all go and pick a dress to wear and they did like a charity fashion show at the hospital.

01:04:49.570 --> 01:05:19.480

Participant 3

Uh, and then there was a gentleman who had had cancer himself, who was a hairdresser. He had his team come in and he got everybody ready, he did their hair and makeup and we all wore beautiful, beautiful, beautiful dresses that they lent to us. And again it was really interesting to see the different types of dresses we all chose to do the show and it was just a really nice experience. And within this group. But you know, you had so many.

01:05:19.850 --> 01:05:39.000

Participant 3

Different ladies, and it was quite strange to be..because of Covid we weren't allowed to meet anymore. But at that time it was just nice. Every few months we'd meet up and you, you've got an opportunity to talk to them, but nobody really talked about their treatment or anything.

01:05:39.600 --> 01:05:46.120

Participant 3

So, I think it was almost like a bit of an elephant in the room. We all knew we were there because we had something in common.

01:05:46.840 --> 01:05:54.080

Participant 3

But that fashion show was a great distraction because a couple of meetings were about that, and you know, we'll do this in the future.

01:05:54.710 --> 01:05:57.620

Participant 3

But although we were together we still didn't.

01:05:58.420 --> 01:06:09.460

Participant 3

talk really, I think that the most vociferous person was one Lady who'd had a mastectomy and chose not to have any reconstruction at all, and she was probably.

01:06:10.880 --> 01:06:22.170

Participant 3

The one who wanted to show us her scar. Show us what it looked like not to have had any treatment, but everybody else in the room was alot quieter so.

01:06:23.280 --> 01:06:26.710

Participant 3

No, so we had the opportunity to talk, but we still didn't do it really.

01:06:27.810 --> 01:06:29.170

Participant 3

That's quite strange.

01:06:30.380 --> 01:06:43.180

Rhian Solomon

So an example of a different type of activity. People to come together to reflect on their experiences. I mean, can you think of other applications of.

01:06:44.370 --> 01:06:46.450

Rhian Solomon

the activities that you've been doing.

01:06:47.100 --> 01:07:03.630

Rhian Solomon

Uhm with this project, are there other places that you think that it might be useful for, well, maybe yourself beyond today or it might be more useful for other individuals or other aspects of services.

01:07:05.060 --> 01:07:05.980

Rhian Solomon

Can anyone think of..?

01:07:05.520 --> 01:07:34.990

Participant 2

I was thinking about a head wrapping workshop. I went to which was just dreadful, like, they were so upbeat and 'Oh well if you tie it like this everything is fine' and like at no one moment in that workshop did the group of us that were there, there was no space for us to say 'it's all abit shit'. None of us wanted to lose our hair. This is a massive compromise however great they were giving some tips and meeting each other, like everything was so.

01:07:35.540 --> 01:07:39.030

Participant 2

Upbeat and solution focused and I guess.

01:07:39.840 --> 01:08:12.040

Participant 2

I haven't quite put my finger on the part that wound me up, but there's. There's something about that may be a creative space where we started with something that we've been able to say in quite a neutral way. Like with the collage (Activity 3) or with.. I don't know. Writing on a hat or so I don't know. That's

something where you could just go. 'This is how I feel about not having my hair at the moment'. And then from that place then move forward with some things and then looking forward to something that happens in the future.

01:08:12.320 --> 01:08:36.940

Participant 2

So, I feel a bit like others have been saying that they're so, I guess, so focused on safeguarding and not letting people say anything unfortunate that can't be managed, but that you can't, you can't say the important things, which is 'we're all here cause we've got this diagnosis' or 'we're all here cause we've lost our hair' and there was no space to acknowledge.

01:08:38.260 --> 01:08:46.040

Participant 2

Like it wasn't like we signed up for an evening course or something. We were there because of a specific thing in common.

01:08:47.620 --> 01:08:48.390

Participant 5

I was definitely.

01:08:47.890 --> 01:08:49.080

Participant 2

Sorry, I'm sounding angry.

01:08:52.150 --> 01:09:05.210

Participant 5

I was definitely thinking that this type of exercise like in...so, like I attend a young women's support group and it's obviously over Zoom at the moment but..

01:09:05.290 --> 01:09:33.060

Participant 5

Uhm, how cool it would be to like use this kind of exercise..So, especially the collage exercise (Activity 3) for example. Like with that particular group 'cause that could be because you know, obviously, that you know these kind of support groups, they tend to follow a very particular pattern and ,you know, which is absolutely fine, but it would just be interesting to then, like, mix it up a bit with having like an actual, practical activity. In that way, you know, assuming that we could be in the same place at the same time, you know, like COVID willing or Covid allowing.

01:09:34.310 --> 01:09:40.940

Participant 5

But Oh yeah, this is the thing I was thinking. I don't know if this is a bit sort of, I don't know how useful this is, but..

01:09:42.480 --> 01:10:12.500

Participant 5

The one thing that's always struck me through this process, it's like so obviously there's, you know, there's things that are available to myself. Like as the patient. But then I was thinking about like what about like? You know my husband, like? What about, you know, family members? And how sometimes that, you know, it's uh, how useful it would be for them to also be able to have this sort of support. This type of support as well. You know, to talk about their emotions, cause it's, you know, obviously, they have obviously a lot of feelings as well. And I was thinking, oh it would be really cool if they could also do something like this.

01:10:12.590 --> 01:10:17.670

Participant 5

They could have a chance to, you know, maybe express themselves in that way, 'cause they probably, they have.

01:10:18.400 --> 01:10:34.790

Participant 5

They are having, you know, obviously related, but a different, probably different types of emotions unintentionally, and things that they maybe don't want to say, or that they can't say, or because they don't want to worry you etc etc. So, I feel like it could be, in an ideal world..it could be extended to, you know, family members essentially.

01:10:38.600 --> 01:10:46.030

Participant 4

Yeah, hard to be the one with the diagnosis, but it's hard to be somebody watching it happen as well.

01:10:47.000 --> 01:10:48.030
Participant 4
A difficult place.

01:10:53.590 --> 01:10:59.920
Rhian Solomon
Anyone else have anything to add about? Any other opportunities that you think there might be with this kind of?

01:11:01.030 --> 01:11:02.160
Rhian Solomon
Activity

01:11:04.110 --> 01:11:06.050
Rhian Solomon
Or that would be useful for clinicians.

01:11:08.720 --> 01:11:09.170
Participant 6
Yes.

01:11:11.020 --> 01:11:18.730
Participant 6
I think it would be. I think it's just a little creative element. UM, 'cause I've spoken to the surgeons on a sort of..

01:11:19.480 --> 01:11:43.100
Participant 6
I've taken templates in with me and things like that and said 'look, this one doesn't quite match this one' and they've actually quite enjoyed that. They've actually quite embraced that. Like oh, she's a bit weird. A bit different, but you know, like that kind of thing that they, I think they sort of appreciate. It's probably not what they see on the normal basis, but I think it would be good for them, as well, to do something a little different. Look at things from a different perspective.

01:11:44.120 --> 01:11:44.910
Participant 5
Yeah, I think.

01:11:44.300 --> 01:11:48.290
Participant 6
'cause it's so magical it's quite, you know, quite intense and.

01:11:50.230 --> 01:12:08.580
Participant 5
Yeah, I think. I think it's really helpful. I think it should be advocated for, for sure, and I think you know, going back to what Participant 2 was saying about starting that type of class with some kind of creative activity, like I mean, just as like. So I used to teach and I feel like that's such a wonderful way to kind of bring something up in a way that is like not.

01:12:09.890 --> 01:12:21.560
Participant 5
It it it's? It's not so full on. You can actually process your emotions through something a bit more, kind of, more concrete, something with materiality, and I think maybe that's easier for people. So you should definitely steel Participant 2's idea.

01:12:24.580 --> 01:12:25.130
Rhian Solomon
Well, I'm

01:12:24.740 --> 01:12:45.910
Participant 2
I think something about helping male plastic surgeons to realize that, I don't know. I went to a reconstruction seminar and then PowerPoint slide number 13 is flashed up. The dreadful bra from Asda that they recommend you get and like, just do they understand what that feels like.

01:12:44.370 --> 01:12:45.100
Participant 6
surgeons.

01:12:46.830 --> 01:12:54.610
Participant 2
To see that that thing that looks ugly and it's for an ugly reason and for them not to realize that.

01:12:55.440 --> 01:13:05.260
Participant 2
Even though we've heard all sorts of complicated stuff before that slide and all sorts of complicated stuff after that, so even those slides are a trigger for a woman. And does he know that?
01:13:06.150 --> 01:13:06.740
Rhian Solomon
Umm?
01:13:08.070 --> 01:13:09.970
Participant 2
Maybe other people got better seminars than I did.
01:13:11.280 --> 01:13:11.740
Rhian Solomon
This is..
01:13:11.300 --> 01:13:17.890
Participant 6
You've got the same surgeon as me, 'cause that's exactly the same bra, the Asda zip up front bra was the one that was recommended.
01:13:20.870 --> 01:13:24.090
Participant 6
Tell me, 'get it £9'. I remember him telling me. He even knew the price.
01:13:25.170 --> 01:13:26.320
Participant 2
Maybe they're on commission.
01:13:25.900 --> 01:13:26.800
Participant 6
It's amazing.
01:13:27.780 --> 01:13:28.410
Participant 3
Yeah.
01:13:29.560 --> 01:13:30.050
Participant 5
Damn.
01:13:30.450 --> 01:13:42.350
Rhian Solomon
Do you think there's an opportunity to gain more insight about your experiences that, you know, the kind of outputs or things that you've created from these activities, might
01:13:43.290 --> 01:13:44.200
Rhian Solomon
Open.
01:13:45.080 --> 01:13:57.170
Rhian Solomon
Dialogues, let's say, or open conversations in a different way, maybe with family members. Participant 5 you talked about, maybe potentially with clinicians. Do you feel that, you know, the things that you've created?
01:13:58.840 --> 01:14:04.060
Rhian Solomon
Have other uses, let's say so to hold some of these conversations maybe.
01:14:05.330 --> 01:14:10.640
Participant 3
I think with the UM, the front and the back of the garment..(Activity 3 - collage)
01:14:11.120 --> 01:14:23.120
Participant 3
Uh, so my son happened to be home on the day I was doing the collage and I see the back being very very different to the front but.
01:14:23.680 --> 01:14:25.260
Participant 3
For me to be able to say to him
01:14:26.000 --> 01:14:55.580
Participant 3

'cause we, we'd actually been to the Saatchi Gallery a couple of weeks ago and we were looking at these.. thinking 'why would people put that? Why is that there? I don't understand what does this mean', and then suddenly I've created something that in my head makes so much sense, but someone else looking at it..so he's like 'mum, what have you put? What does it mean?' And I'm like, 'well, this means this and this is this and this this' so it's like it was amazing to put all these different things.

01:14:56.050 --> 01:15:15.270

Participant 3

That really meant a story to me. It was unfolding on the back (collage) and then when I got to the front it was like oh, this is a really nice story on the front, but there was still a little element. I've put a little black bit on the front 'cause in the back of your mind, for me, there's always this little something.

01:15:15.860 --> 01:15:33.590

Participant 3

Uhm, but even within that it was like the front is such a happy place. But again I had to explain to him why, why it was my happy place and I think that maybe sometimes, like you say, even with your surgeon or whoever it may be, the Oncologist.

01:15:34.670 --> 01:15:46.100

Participant 3

If they could see what women have created down the line, as we all have, what was our thought process? What? Because they're the medical people, they want to fix you.

01:15:47.390 --> 01:15:54.670

Participant 3

But sometimes it's what's going on in your head comes afterwards because you're so busy having your treatment.

01:15:55.250 --> 01:15:56.530

Participant 3

And then eventually.

01:15:57.130 --> 01:16:15.470

Participant 3

You kind of get to think little bits, and I don't know for me. I allowed a bit in and out at a time. I never sat there and thought everything at once and it just comes in waves really. So I think the garments (collages) were a really, really good idea for other people.

01:16:16.510 --> 01:16:19.830

Participant 3

To think gosh, what were they thinking? What does that actually mean?

01:16:24.800 --> 01:16:31.540

Rhian Solomon

Would you let clinicians see your wardrobe? Is that what you're saying? As in, you know, talking through them?

01:16:29.300 --> 01:16:29.600

Participant 3

Yes.

01:16:31.890 --> 01:16:41.430

Participant 3

Well, I think, I think it's the garment (collage). It's the back and the front of the garment that is the most significant thing through the whole workshop process because.

01:16:42.930 --> 01:16:45.780

Participant 3

Although you are in effect, decorating.

01:16:46.420 --> 01:16:50.220

Participant 3

the garment, you're actually, really, putting your emotions.

01:16:50.950 --> 01:17:03.250

Participant 3

Especially on the back, I think emotions that you've learned to suppress, you allowed to come to the surface, and that's why for me it took me a day 'cause I had to keep coming backwards and forwards to it.

01:17:00.610 --> 01:17:01.080

Participant 5

yeah.

01:17:04.920 --> 01:17:09.240
Participant 3
So, I think, they probably speak volumes about us.
01:17:10.240 --> 01:17:12.170
Participant 3
As to what you've put on there.
01:17:13.290 --> 01:17:19.850
Participant 3
And that's not a bad thing. I think that, you know my surgeon was amazing. A really, really lovely person.
01:17:19.910 --> 01:17:38.490
Participant 3
And obviously he sees hundreds of women, unfortunately, but we've all got these thoughts, but they are so busy they can't..And also it would probably be unhealthy for them to take on every single one of us, our emotions, how we're feeling.
01:17:39.160 --> 01:17:39.760
Participant 3
That they.
01:17:40.390 --> 01:17:45.210
Participant 3
They just, you know, they want to fix you and thank goodness my surgeon did fix me.
01:17:45.920 --> 01:17:47.760
Participant 3
Um, but it's..it's yeah.
01:17:48.850 --> 01:17:56.110
Participant 3
There's a lot of thought that goes on after, I think you have the physical side of it and the mental side of it comes.
01:17:57.110 --> 01:17:58.930
Participant 3
Maybe a little bit afterwards.
01:17:59.520 --> 01:18:04.910
Participant 3
Or maybe that just depends on what treatment you've had as well. I mean, like you know, all of us, we've all had.
01:18:05.890 --> 01:18:07.040
Participant 3
Different treatment.
01:18:07.810 --> 01:18:09.050
Participant 3
The same, but different.
01:18:12.140 --> 01:18:23.750
Rhian Solomon
So I just wanted to clarify if you meant that these activities are a way of kind of consolidating your experience because it's obviously an ongoing experience and across quite a.
01:18:24.530 --> 01:18:37.330
Rhian Solomon
Of course, quite a big period of time and there's a significant experience, but that you.. The activities are kind of consolidated and you're thinking of like consolidating it..
01:18:27.460 --> 01:18:27.900
Participant 3
Yeah.
01:18:34.570 --> 01:18:34.870
Participant 3
Yeah.
01:18:36.240 --> 01:18:36.580
Participant 3
Yes.

01:18:38.120 --> 01:18:45.630

Rhian Solomon

Into a thing and a collage obviously or an object that you've chosen.

01:18:45.950 --> 01:19:02.900

Participant 3

Yeah, I think that when you are diagnosed and then you read these things, your journey, you're a warrior, you're this, you're a that. Actually, you're a scared person who's unwell who wants to get better and I don't want to be given a label of..you're this warrior. No, I'm just.

01:19:03.640 --> 01:19:04.310

Participant 3

I'm just.

01:19:04.880 --> 01:19:11.160

Participant 3

I just don't want this. I want to get better and I will do anything it takes to get better and.

01:19:11.770 --> 01:19:17.890

Participant 3

Be, to my family and to my friends, what they've always seen me as, um..so.

01:19:19.370 --> 01:19:21.130

Participant 3

Yeah, I don't really know what I'm trying to say, I just.

01:19:22.370 --> 01:19:40.220

Participant 3

I just think this has been very helpful. Like you say, the nine items or looking at the colours you used to wear, to the colours you're wearing today, but it's been nice that we can do... You've given us enough time that we can come and go to it. We can. You're not suddenly put in an environment where.

01:19:41.710 --> 01:19:53.910

Participant 3

When you say something, once you put it out there. You can't take it back, but what you've given us, by doing this process, you've given us the time to allow us to express ourselves in the very best way we can.

01:19:54.980 --> 01:20:02.460

Participant 3

And now I really appreciate that. That I've been able to come and go, and you've probably got the best of me.

01:20:03.710 --> 01:20:05.620

Participant 3

The most truthful me.

01:20:06.330 --> 01:20:06.890

Participant 3

Within.

01:20:07.810 --> 01:20:09.360

Participant 3

This booklet so.

01:20:13.370 --> 01:20:33.450

Rhian Solomon

I'm really looking forward to receiving all of the things that everyone has made in your booklet.. I'm conscious of the time because I don't want to keep you guys longer than we planned, but I'm wondering how people feel kind of moving forwards from doing this this activity.

01:20:35.390 --> 01:20:43.490

Rhian Solomon

So how does it feel moving forwards from them now?

01:20:44.570 --> 01:21:15.620

Participant 5

So I was thinking that because I have BRCA gene 1, I've got like a preventative mastectomy and reconstruction coming up next year and I was thinking how the..you know, moving forward. Like it's well. I guess two things. The first being is that it has kind of allowed me to. I think it's allowing me to go into that surgery much clearer eyed and in a better sort of situation really 'cause I'm, I'm sort of. I'm taking those experiences that I've, you know, been able to process those experiences from last year and.

01:21:15.930 --> 01:21:19.530
Participant 5
Then bring them with me, hopefully in a in, in like a positive way and then.
01:21:19.580 --> 01:21:21.980
Participant 5
Uhm, I can't remember what the second thing is now..
01:21:23.220 --> 01:21:28.180
Participant 5
Lost my train of thought but yeah, I think it. It, it's and I think it is.
01:21:30.460 --> 01:21:46.020
Participant 5
Yeah, I was gonna say was that I mean in some ways, in a weird way I could next year when I have my mastectomy and reconstruction. Then afterwards. Like I'm, I'm thinking to myself. Oh, then maybe I could do like my own version of this, you know, like do it again and actually you know, see how, see how different it is.
01:21:46.850 --> 01:21:54.200
Participant 5
So you can see if anything has changed. If anything. I mean maybe it will be the same, I don't know, but.
01:21:54.770 --> 01:21:55.460
Participant 5
Uhm?
01:21:56.290 --> 01:21:58.560
Participant 5
Yes, I think that that's what I plan to do.
01:22:00.900 --> 01:22:04.830
Rhian Solomon
Thanks Participant 5. And how does everyone else feel?
01:22:04.280 --> 01:22:35.430
Participant 6
I'd just like to keep the creative side going and I've got it sort of going doing this. I'd just like to just keep doing stuff. No, it doesn't necessarily have to be all about the same thing, but the process of just doing the creative side of it. It just opens up a whole load of, you know, getting out emotions, getting out other things. It's something for me to do, so I just want to keep doing that. Really, I don't know in what, just using different media and we spoke about printing things that we have done that before. I spoke to you about that.
01:22:35.730 --> 01:22:37.800
Participant 6
So I just want to try lots of different creative things.
01:22:45.300 --> 01:22:45.990
Rhian Solomon
Anyone else?
01:22:45.650 --> 01:22:49.540
Participant 4
Yeah, really enjoyed the creative aspect. I haven't done anything, sort of.
01:22:51.070 --> 01:22:58.580
Participant 4
Well, since I've been helping my son with primary school homework, we haven't done anything like that, so, I just really enjoyed. Really enjoyed it.
01:23:00.300 --> 01:23:03.000
Participant 4
Um, yeah drawing. Maybe try drawing again.
01:23:07.980 --> 01:23:08.350
Participant 4
Good.
01:23:11.030 --> 01:23:13.100
Rhian Solomon
Participant 2 is there anything you want so add?

01:23:14.150 --> 01:23:23.920

Participant 2

Um, just I really appreciated it and I probably didn't realize how much work I've still got to do, sort of.

01:23:24.800 --> 01:23:31.460

Participant 2

Processing things or being able to share stuff with my husband and things like that, so I guess it's.

01:23:32.290 --> 01:23:48.810

Participant 2

Pondering what I do before the envelope goes (returning the Wardrobe Probe) and what I do when the envelope comes back, but really appreciate this chance for a bit of a stock check and really enjoyed finding my kind of inner Banksy. That was great fun.

01:23:52.060 --> 01:23:54.710

Rhian Solomon

I can't wait to see your T-shirt.

01:23:54.850 --> 01:24:00.430

Rhian Solomon

You sound really inspired by that activity which is really good to hear.

01:24:00.480 --> 01:24:06.440

Rhian Solomon

Yeah, I'm gonna draw the focus group to a close 'cause we've been chatting for a little while.

01:24:06.930 --> 01:24:15.600

ACTIVITY 2 GARMENT PATTERN MAPING



Question

Do people notice?

Who am I now?

? Is there ever too much talk about it?

WHAT'S NEXT?

yes, what is that about?!

Why's there still so much pinkification?

↳ We're not little girls!
↳ It isn't a girly, fluffy experience!!

Reassurances

You are not alone.

You disclose it your way (not appearing like dressed smoke + mirrors) → control.

great boobs + cleavage

GETTING TO KNOW YOUR BODY

* Getting through this experiences means you can get through * anything. Nothing really scares you now.

ongoing medical support

It is us to hear stories of others

part of life

ACTIVITY 3 - DRAFTING DESIGN CHALLENGES

How Might We...?
Create inclusive services for men/minorities so that everyone feels supported?
Inform next steps so that people are reassured?
Gain access to speak with other women with same diagnosis and plan?
Give information to people when they are emotionally ready to receive?
Build a workbook or journal to help women document/prompt questions?
Create an online show and tell to navigate through reconstruction and see how it looks?
Offer personalised info and support to different groups so that each person has access?
Be appropriate with friends and family with time we need from them on our cancer journey?
Obtain the relevant info so that less stress, less shock, prepped?
Personalise care options in a short space of time?
Empower the user...create an app that can give bullet point references that come from one place and not multiple sources?
Be interactive with chance to ask questions - webinar? Could be anonymous. Would need to be secure.
Support communication so that patients feel encouraged?
Develop a set of FAQ's as a prompt for newly diagnosed?
Balance someone coming to terms with diagnosis and empower them to ask right questions?
Support empowered decision making?
Give time to medical professionals to explain things?
Have an interactive app for people so they can track their own proposed treatment and have access to info 24/7 (2am).
Train health professionals to see patients as a 'person' and communicate empathetically so they feel seen and heard?
Allow people access to their records to allow them to fully understand their situation and help them emotionally process information?
Collate info so that consistent, easily accessible and relevant?

APPENDIX E.7. WARDROBE PROBE WORKSHOP FEEDBACK FORM

APPENDIX E.7.1. SERVICE USERS

1. Did you find the following activities useful?	
Activity 1 - Engaging with exhibition content (Wardrobe Probe data)	
P3	Yes. It made me realise that other people feel the same as me.
Activity 2 - Collectively mapping the needs of people affected by breast cancer	
P3	Yes. This was useful as you realise that other people have the same questions and thoughts as I do. Also, going forward in the future, hopefully these questions can be addressed.
Activity 3 - Drafting design challenges	
P3	Yes. Hopefully condensing common questions will be helpful to others.
Activity 4 - Constructing the garment	
P3	Yes. It was like going full circle to see the clothing element of people's thoughts.
2. How did you find working with designers/clinicians in this context?	
P3	Interesting. Good to hear other people's thoughts.
3. What worked well during today's workshop? And why?	
P3	Collectively mapping our thoughts. Also, having chance to talk to people who understand what I have been through, with their own treatment.
4. Can you suggest how the workshop activities could be improved?	
P3	No content

5. Have these activities helped you to have new/different conversations with clinicians/designers about your experiences of breast cancer treatment and recovery? If so, please expand.	
P3	Yes, I think people who have had treatment have powerful thoughts. It is good to discuss this with people who are seeing this from another side.
6. What benefits might there be, if any, to using creative, clothing-based methods, such as this, in the design of health services?	
P3	To have opinions of people who have had treatment and how they view their body is important going forward.
7. What barriers might there be, if any, to using creative, clothing-based methods, such as this, in the design of health services?	
P3	I do not think there are any barriers.
8. What alternative applications might there be, if any, for these activities? Please expand.	
P3	No Content

APPENDIX E.7.2 DESIGNERS

1. Did you find the following activities useful?	
Activity 1 - Engaging with exhibition content (Wardrobe Probe data)	
P7	Yes. Great start for understanding the context/pain points and situation. Especially for a person who does not have experience of it. Would like some time to hear people talking over their comments.
Activity 2 - Collectively mapping the needs of people affected by breast cancer	
P7	Best part of the activity. Most of the people were quite engaged and passionate, expressing their concerns/experiences. More time was needed to maybe cover other areas.
Activity 3 - Drafting design challenges	
P7	It would be great to have some time to talk about our Post-its.
Activity 4 - Constructing the garment	
P7	It was a fun activity. Quite interesting, and having a physical object to play around increases engagement of participants and can develop a more open relationship between them.. I believe it can be used in many different scenarios but personally I would add it in between of the activities. The reason is that you probably want to take advantage of the relaxed atmosphere that has been developed between the participants and open up more. Definitely needed more time but having Nic in our team (not sure if she was there as a facilitator?) helped since she was willing to take over.
2. How did you find working with service users/clinicians in this context?	
P7	<p>Most people were quite engaged and happy to share their experiences which was surprising. I think most of our participants were quite open about their experiences and had useful info to add. There was only 1 participant which was quite younger than the rest that I found less involved. I assume that her experience might be slightly different compared to the others (considering her young age) although I found her quite open and transparent about her experience when we had a 1-1 chat. I assume that's always the risk with a workshop and from a User Research perspective we could easily re approach her afterwards.</p> <p>From personal perspective I felt sometimes that people's experience and background was quite intense and me adding a comment might be considered inappropriate. Apologies in advance if I did not read any instructions about our role in the workshop but maybe an observers' guidelines document ahead of the project defining the expectations and behaviour could be helpful.</p>

3. What worked well during today's workshop? And why?	
P7	Peoples availability and how open they are. Didn't feel like I have to be careful with what I'm saying. I think people similar background and ethnographic helped in focusing in a specific area and had a fruitful convo.
4. Can you suggest how the workshop activities could be improved?	
P7	Time added. But also maybe provide some steer. Especially for people who were quiet. As mentioned before, more time was needed. People seemed happy to engage and stay even after the end of the session. Also maybe ask people to talk about their post its so as to increase engagement and have equal time around people. (although everyone seemed to be open and represent themselves equally)
5. Have you learned anything new about patient experiences through these activities? Please expand.	
P7	Although the info access issue, it is common around health areas. It's been disappointing to hear about consistency issues and how harsh people might be. Never considered the combo of menopause and breast cancer and its consequences.
6. What benefits might there be, if any, to using creative, clothing-based methods, such as this, in the design of health services?	
P7	I would like more time to explore it. I guess for body-change health services that could work as an activity for collecting feedback either through observation or based on users' comments.
7. What barriers might there be, if any, to using creative, clothing-based methods, such as this, in the design of health services?	
P7	As mentioned above great activity to improve engagement but can be restrictive based on users' needs and general abilities. (Consider users of different cultural background but also physical restrictions e.g. wheelchair user). If we were planning to design a service around this garment it might be considered biased and solution focused rather than exploring different alternatives. So, it is important in which stage of a project we might use it (ideation or closer to developing a solution?)
8. What alternative applications might there be, if any, for these activities in your sector? Please expand.	
P7	I assume the first part of your research could be used alongside a diary study for collecting feedback throughout the process. In terms of the garment activity, I cannot really think of something specific but as I said physical activities/puzzles like that can be quite encouraging for many different ideas..

1. Did you find the data collected from the probe activity packs (inc. artefacts, written content) useful? Yes/No. Please expand.	
P7	Very useful to set the context!
2. Have you learned anything new about patient experiences by engaging with content from the packs? Please expand.	
P7	Learned about the online search and support you can get. People seem to rely on that more than the Dr's sometimes.
3. What benefits might there be, if any, to using creative, clothing-based methods, such as this, in the design of health services?	
P7	Keeping people engaged. Displaying artefacts in a physical space.
4. What barriers might there be, if any, to using creative, clothing based methods, such as this, in the design of health services?	
P7	Limited to physical attendance.
5. Can you suggest how the activity pack could be improved?	
P7	Would be great to have more info about the clothing part. Was not entirely sure of the last activity (in the workshop – Constructing the Pattern Map).
6. What alternative applications might there be, if any, for using the activity pack (or activities within it) in your sector? Please expand.	
P7	We could consider how this condition might have an impact on different projects, when the focus is not on breast cancer. But other user groups. might be patients etc.

APPENDIX E.7.3. CLINICIANS

1. Did you find the following activities useful?	
Activity 1 - Engaging with exhibition content (Wardrobe Probe data)	
P12	Yes. Exhibition content meant you could start to engage with the topic, understand somewhat what others felt therefore opening your mind to a wider conversation, and also it enabled others to engage with each other and start conversations about serious issues which may otherwise not have been started.
Activity 2 – Collectively mapping the needs of people affected by breast cancer	
P12	Yes. Again it opened the door to a deeper conversation as well as bringing in topics and needs that as an individual you may not have considered before
Activity 3 - Drafting design challenges	
P12	Yes. It was good to have a design challenge and a focus point to steer the conversations, and enabled everyone from whichever point of reference that were coming from, to have a say, and to think more laterally and physically rather than keeping on the emotional aspects of cancer care. It was interesting to change the conversation from what is wrong to what can be done.
Activity 4 - Constructing the garment	
P12	Yes. I found it to be useful as it felt more of a collaboration with each other, because it was hands on, quick, and you could see a product at the end, which felt like you had achieved something rather than just concepts. It really bought everyone together in a different way.
2. How did you find working with service users/designers in this context?	
P12	I loved working with the patients and designers. I am very used to working with patients and found it really exciting to be with service designers and researchers as they have such a different mind-set that was thoroughly refreshing and exciting, like actually things can be changed for the better whilst we have people like JS working as a service designer.
3. What worked well during today's workshop? And why?	
P12	I found the circular seating, the small tasks, the openness of the conversation all worked really well, because it kept everyone together, there was no one leading or being able to hide and it felt practical and engaging without any pressure.

4. Can you suggest how the workshop activities could be improved?	
P12	I thought it worked really well for the information I took away from it, but I guess I was a bit unclear as to the main objective, therefore unclear where we were supposed to be headed and finished. Perhaps the timeline needed to be adhered to better, and this often means cutting in to conversations and verbally moving people on. There is a balance between letting people engage freely and herding them gently in the direction you want them to go. I guess that is just confidence and time management.
5. Have you learned anything new about patient experiences through these activities? Please expand.	
P12	Yes definitely and mostly the need to full information, clarity within information, and a general timeline of information to try and lessen the shock the patients are already feeling from their diagnosis. But also the luck of the draw with which consultant / practitioner you are assigned too.
6. What benefits might there be, if any, to using creative, clothing-based methods, such as this, in the design of health services?	
P12	I think the benefits are that it gets patients thinking about their experience through a basic need like clothing that opens their thoughts to why, how, what they experienced by using a very natural, common, everyday part of their life, to show up the changes, emotions and thought patterns they had experienced without potentially realising it was going on. It allows a safe space for people to truly explore their emotions and the changes they experienced, in order to find out what they needed, had, would have liked during that process. It's a catalyst to some answers that may not have been observed or remembered otherwise.
7. What barriers might there be, if any, to using creative, clothing-based methods, such as this, in the design of health services?	
P12	I don't know of any barriers, but would like to know what others thought.
8. What alternative applications might there be, if any, for these activities in your sector? Please expand.	
P12	In medical tattooing - it could be used to determine what patient's needs during their treatments, what could aid the process from finding a practitioner to the final results.

1. Did you find the data collected from the activity packs (inc. artefacts, written content) useful? Yes/No. Please expand.	
P12	Yes, definitely, it's interesting to see how people express themselves and their experiences, especially with colour and words.
2. Have you learned anything new about patient experiences by engaging with content from the packs? Please expand.	
P12	Yes, I think the hidden information was a very good way to see what people feel but don't show. That was very clever, very simple and enabled people to tell part of a story that otherwise they may not have mentioned.
3. What benefits might there be, if any, to using creative, clothing-based methods, such as this, in the design of health services?	
P12	Maybe it's just a way to get people speaking, to start a conversation with a safe and easy language that people already know. Clothing is often about how we express ourselves so it allows people to concentrate on the expression of the outfits and the artwork rather than just on themselves, it takes away that self-consciousness that some may be feeling.
4. What barriers might there be, if any, to using creative, clothing based methods, such as this, in the design of health services?	
P12	I'm not sure about the barriers?
5. Can you suggest how the activity pack could be improved?	
P12	Improvements - gosh I don't really know. I thought it was great and didn't consider any improvements.
6. What alternative applications might there be, if any, for using the activity pack (or activities within it) in your sector? Please expand.	
P12	I think for Medical Tattooing we are often speaking about confidence and feeling comfortable in your own skin. To see how clothing changes pre and post Med Tat would be interesting because often people are hiding visible differences with certain types of clothing - long sleeves / high necks / long trousers; so, it would be interesting to see how much confidence the treatment gives them, and whether that changes in their day-to-day life. Also, what their feelings are about their visible difference and the hidden words that they don't mention to friends, family and potentially even their practitioner.

APPENDIX F ANALYTICAL APPROACH SAMPLES

APPENDIX F.1. PHASE 1

APPENDIX F.1.1. FACILITATOR INTERVIEWS - TERESA ALMEIDA

<p>¶ Rhian Solomon: → I was going to say it's incredibly broad. Yes. No, it's just really nice to have that background as well to what you do. The next question I was going to ask you was: What role do materials and/or objects play within your practice? ¶</p> <p>¶ Teresa Almeida: → For me, I see all these objects, all the materials that I use as essential for the practice. I definitely see them as catalysts for these discussions, for these conversations around all these sensitive topics. I think they are a way to break the ice, and then to start with, it's a way to actually reach out to these different communities of women that I work with. It facilitates that first approach. ¶</p> <p>¶ It also facilitates, for example, doing the workshop. It facilitates their conversations around the table — yes, I think coming in with a set of creative materials and the kinds of materials or the kinds of objects that let people in a workshop actually discover different things and do on their own. It definitely makes it easier to talk about things you wouldn't talk about otherwise. That's how I've been using these different materials and these different accessories, objects or artefacts then. ¶</p> <p>¶ Rhian Solomon: → Okay, so I'd like to talk to you about your PhD project and the role that materials and/or objects that you employed within that project, but also your role as a facilitator in that project. Can you describe the materials and/or objects that were used in these activities? You might want to give a bit of background about the particular project as well beforehand, actually. ¶</p> <p>¶ Teresa Almeida: → Yes, so my PhD work is called 'Designing Technologies for Intimate Care in Women'. What it is about: it all started with thinking about pelvic health in women and how this was somehow something that wasn't really known to most women at different stages of their lives. ¶</p> <p>¶ It's also something that is not included in the curriculum, at least in the UK, and as far as I know, nowhere else in the world. It could be part of Sex Ed, for example, but no part of Sexual Education in schools includes pelvic health, but which is very important not only in relation to sex but also in relation to things such as body posture and to all kinds of more complicated illnesses and disruptions that come to a woman's body with time, after childbirth, etc., by organs moving from place to place. ¶</p> <p>¶ It's a very complex system, our body, and areas are easily neglected. I was thinking at the time of how to actually design in a way that could promote preventative care in pelvic health. I focus on women. Of course, men also have these kinds of issues or they have similar types of issues, but I focus on women. I thought, "Okay, so let's find a way that's easy enough, that's not medicalised — find ways to share this information and understand this information so that it can contribute to a healthy..." ¶</p>	<p>¶</p> <p>¶ Code 1: NHM—HM· Materials· catalysing· complex· conversations· To· break· the· ice· And· reach· out· to· new· communities·E·¶</p> <p>¶ Code 46: NHM—HM· Materials/objects· to· discover· things· independently· Eases· conversations·E·¶</p> <p>¶</p> <p>¶</p> <p>¶</p> <p>¶</p> <p>¶</p> <p>¶</p> <p>¶</p> <p>¶</p> <p>¶</p>
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<p>Not even a healthier lifestyle, but thinking about the body throughout the life course and how it changes, and start to think about it not only at the stage where you have to go and see a doctor, but actually understanding how the body works and maybe even not ever have to go and see a doctor at the time, focusing on incontinence and looking at urinary incontinence. What is, in teenagers, giggle incontinence? Why does it happen? Is it normal? Isn't it normal?</p> <p>So all of this is helping you want to tackle it in a way that is not scary because incontinence can be really scary for some women if they don't understand what's going on. Also, it's how to make it accessible in a way that is not medicalised, and it's also fun to learn about. It also makes it easy to come across, as in our bodies are normal, we have all these different bodily fluids, all these different things that happen.</p> <p>They're all normal, but we need to learn that that's true because, otherwise, any event that happens, any disruption, if we're using this 'body disruption' concept, anything that happens is scary and it's a taboo, so you don't really talk to anyone. You wait way too long before you go and see a doctor, etc.</p> <p>So it's how to make this a little bit more of a common language, how to make it more... Yes, I like the word 'accessible'. I think it sums up the idea behind coming up with all these different material kits that I created at the time. I explored these toolkits with a wide age range. Sorry, I'm just rambling now. I don't know where to start.</p> <p>Rhian Solomon: → No, no, it's great.</p> <p>Teresa Almeida: → So the first toolkit was an electronic textile toolkit. I'd done that in the past, so it had this little bit of technology. It also had the aesthetics and it had the interactive components that I was interested in exploring in this new toolkit that, potentially, could help advance this kind of discussion.</p> <p>I had workshops. I first had the workshop with young teenage girls aged 15 to 16. That was really interesting because the toolkit was designed for an awareness of the pelvic floor and the pelvic floor muscles.</p> <p>I went in assuming that girls at 15 and 16 knew a little bit about their bodies, so they would actually have a basic understanding of where they pee from, where the menstrual period comes from that and all of that because, supposedly, they also learned that in school. I'm not saying at home, but at least in school, they would have learned that.</p> <p>The surprise at the time was, "That's not true, actually." A lot of these young women had no idea what was going on, at a very basic level, in their intimate body and these different bodily functions. So that was really interesting. It made me take a step back, include a few more materials, and also make the decision to have the workshop with women from different generations.</p> <p>So I had a workshop with women in their 20s, 30s. I had another one with women all the way up to 40s, 50s. I had another workshop at a women's centre with migrant women. I don't recall their ages, but I would say they were all under 20s, 30s, but from different backgrounds – mostly South Asian. It was really interesting also to see the social, cultural background and how either sex or the understandings of the body might vary - so exploring it from a different context.</p> <p>Rhian Solomon: → Absolutely.</p>	<p>Code 13-NHM-HM-Materials and objects to make knowledge accessible. Reduces fear. E.</p> <p>Code 13-NHM-HM-Materials and objects to make knowledge accessible. Normalises complex health conversations. E.</p> <p>Code 16-HM-HM-Demographics (cultural background/age) affecting bodily knowledge. Shapes workshop participation. E/C.</p>
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F.1.2. WRITTEN REFLECTION – RHIAN SOLOMON

I feel that the venue for the workshop could have been improved. Being in a hospital wing after hours, can be a bit eerie, as there's very few staff in the department. The patients taking part in the workshop also weren't very familiar with the space as they hadn't been treated in this hospital and needed guiding to the allocated room, so it created some practical challenges of way-finding. The hospital had been very accommodating as an employer, in how I worked in the department, however, there were a few limitations on how I could work with patients. It wasn't recommended to work with patients off site. Having a staff contract was useful, though, as I could book rooms across the hospital sites for different activities. So, in some ways, I feel like there was a freedom in being employed by the hospital, but at the same time, this came with certain limitations. In hindsight, I think this is why I spent the latter part of the residency running activities out of the Maggie's cancer centre that was based at Singleton Hospital - a very different type of space for patients to just be. I think that it's probably worth spending some time exploring spaces available for any future residencies or workshops that I do, especially if they are on hospital grounds. There were definitely a range to draw on at Morriston and Singleton hospitals but this just needs a bit more time and consideration.

Also, thinking about the workshop space itself a bit more, I think that the space that we used was quite clinical due to the nature of its use and the lighting within it. This may have been familiar, for the surgeon, perhaps helping him to maintain his professional role to a degree. The patients, however, were unfamiliar with the space and the department. However, I think this could also have had its benefits in affording some geographical or emotional distance from their surgical treatment, in that it wasn't the space in which they had had their surgeries or had pre/post operative consultations. It was quite an alien space for the patients, though, as it was not allocated for patient-facing activities. I think in the future, if there was time, I would consider the relationship that all workshop participants have with the space in which facilitated activities are being held. What is the conventional use of the space and how do workshop participants relate to it in context?

Commented [MOU1]: Code 43 HM-NHM Participants attending workshop in unfamiliar space in hospital. Creates problems in locating the workshop. C.

Commented [MOU2]: Code 45 HM - NHM Healthcare organisation providing formal contract for Facilitator. Supports access to facilities to run workshops. E.

Commented [MOU3]: Code 43 HM - NHM Facilitator running workshops in hospital spaces. Creates familiarity/unfamiliarity for Dr/Patient participants. E/C.

Whilst the space was a bit odd, I feel that changing its layout helped to make a more intimate setting, with everyone sat around the same table. Changing the ratio of patients to clinicians was also interesting - The consultations that I'd sat in on in clinic usually had 1 patient, sometimes with a family member/friend, and 2-3 medical staff including the consultant surgeon, a registrar and nurse. I think that changing the space and numbers, seemed to support less formal conversations in contrast to clinical consultations. The surgeon was still leading the session, however, so I don't feel that we fully moved away from this set-up. But the conversational style of the workshop suggests so. Perhaps, this also had something to do with people *doing* creative tasks as opposed to just talking. Having something to talk through, stitching activities to get on with, whilst exploring different surgical topics. In the future, in mixed workshops like this whereby I have participants with differing roles and experiences, I would consider the numbers of participants. Is it important to have equal numbers to try to support representation and equality in conversation?

I was really grateful to the surgeon running the session in stepping outside of his formal role. I wasn't sure whether this kind of activity may be intimidating for him, being slightly outside of his day job and being uncertain as to how the workshop would go and what the patients may ask. I was lucky to find Jon as he had the technical skills to convey surgery clearly to the participants. He also had a friendly character and an openness to test new things. It was helpful that he had a rapport with the patients already, however, this was through different types of interactions in clinic. But I do feel that this helped with connecting with and engaging the women – he was a familiar face. Jon was a trainee surgeon and, perhaps, was keen to explore different formats for working. He may also have been easier to recruit to lead the session due to this. From past experience, consultant plastic surgeons have been difficult to pin down. I think that it takes a bit of time to find the right collaborators and I was only able to afford this, by having spent some time in the department as part of the residency. This, however, is not always available to Facilitators. So, mechanisms to quickly build rapport with possible collaborators is necessary. Attending or designing relevant matchmaking events may well be necessary.

Commented [MOU4]: Code 14 HM - HM Facilitator adapting ratio of workshop participants. Disrupts norms of clinical practice. E.

Commented [MOU5]: Code 27 HM - NHM Facilitator engaging the materiality of space. Provides more relaxed environment. Supports less formal conversations. E.

Commented [MOU6]: Code 6 HM-NHM Facilitators using domestic craft practices. Subverts roles of care. E.

Commented [MOU7]: Code 24 HM-HM Professional Co-Facilitators enable access to workshop participants. Enhances engagement of workshop participants. E.

Whilst I had initially tried to recruit a female surgeon to lead the workshop, I'm not sure whether this was entirely necessary. I think I was keen to explore this as most of my interactions with surgeons across my career and within the residency, had been with male surgeons (most likely due to the lower numbers of women becoming plastic surgeons). In contrast, most of the patients being treated in the context of the residency, however, were female. There's a clear disproportion of gender in both contexts. I think I was keen to see whether there was a difference in how the female surgeons related to the patients? But this is another project in itself. Something to perhaps explore in future iterations?

I realise now that the Arts in Health coordinator, who was a trained nurse in a previous life, played an important role in the residency and supported the smooth running of the workshops. She organised presentations of my practice to the full surgical team, early on, which, I think, demonstrated to the surgeons that I had a genuine interest in their specialism. She also made sure that I had an honorary contract within the hospital trust which allowed me to dot between the different departments in the hospital, to meet the staff and get informed in quite an informal way which helped me to work out how I could develop activities that were useful for both the patients and staff there. I believe that these things also helped to recruit staff and patients to the workshops that I had designed, including the nipple reconstruction workshop. The residency was also 18 months long, on a part time basis, so it offered a good amount of time to get to know people and build a bit of trust and to allay any fears about what an Artist was going to do in their department. I felt really conscious of just *landing* in the department as an 'Artist in Residence' and people being confused or concerned about my intentions. In clinic, I remember spending a fair bit of time explaining to differing members of staff and patients, who I was, why I was there and what I was aiming to do. I got better at conveying this as the residency progressed and as things became clearer. Thinking about it, residencies have been the main way that I have practiced as an Artist as they provide focused periods of time for experimentation and exploration of subjects. I think that time is necessary not only to find collaborators, but also to assure potential future participants of your intentions, especially, in this case, as a non-clinician, of being from quite a differing specialism, not normally associated with a hospital and the services that it provides.

Commented [MOU8]: Code 31 HM - HM Facilitator being visible to participants. Supports recruitment of participants. E.

Commented [MOU9]: Code 44 HM - NHM Facilitator undertaking long/part time contract. Built trust with staff and patients in clinic. E.

Commented [MOU10]: Code 44 HM - NHM Facilitator undertaking long contract. Provided clarity in defining/communicating Facilitator intentions. E.

F.2. PHASE 1 COLLATION OF DATA OUTPUTS

Key – Facilitator Participants

Yellow – Teresa Almeida

Teal – Seamus McGuinness

Grey- Celia Pym

Green – Annette Schwalbe

Turquoise – Rhian Solomon

CODE 1

Code 1 NHM – HM Materials catalysing complex conversations. To break the ice. And reach out to new communities. E.

I definitely see them as catalysts for these discussions, for these conversations around all these sensitive topics. I think they are a way to break the ice, and then to start with, it's a way to actually reach out to these different communities of women that I work with. It facilitates that first approach.

Code 1 NHM – HM Materials and making catalysing conversations. Overcomes taboo health topics. E.

Yes. Yes, so basically, using materials as catalysts for igniting these discussions... I think it goes back to this idea that when you're actually making or when you're doing something, you're not just looking at someone talking to you... It's not a lecture kind of environment. You're actually multitasking. Like with the pattern, you're cutting at the same time as you're talking to someone next to you. It feels from what I observed and also from this experience that it actually makes it a lot easier to talk about things you wouldn't talk about otherwise.

Code 1 NHM – HM Materials and making catalysing complex conversations. Enhancing access to bodily knowledge. E.

I think that was one of the objectives, actually – to create this kind of environment that lets you learn these different things through making things. Instead of complicating them, you just make them easier because you're doing all these different things at the same time, and without noticing, you're already talking with someone you'd probably not talk about these issues with. It just makes things feel a little bit more natural. Yes, I still feel that way. I think it's a good way to bring in these different topics to someone who might not be used to talking about these topics, and bring it to them in a way that is just very clear. It's simple in its approach. Yes, it's the opposite of complicating with jargon and things like that. You just make it accessible, yes.

Code 1 NHM – HM Materials and making catalysing complex conversations. Enhancing access to bodily knowledge. E.

It's going back to the basics. You can't really complicate things. You can't really know the complexity of the body without understanding the basics of the body. So maybe starting from there is a way to go. I imagine, thinking about the confused looks I saw in this clinic, for example, maybe that's the way to go, really. You don't have to even explain where the bladder is. Well, in a cross-section of the body, maybe...Yes, we have to find different ways to show where the bladder is and how that might be connected to the pelvic floor muscles in a way that is less abstract, in a way that people can actually feel on their bodies. I don't have an answer to it. I've just been speculating and exploring different ways that I can possibly do it. Yes, I lost track again, sorry.

Code 1 NHM – HM Materials catalysing complex conversations. **Enable personal validation and self-expression. E**

The body maps were a therapeutic tool in the group in which they were creating them to share and feel a bit more deeper and have their own experiences validated as well as then using them as documents in which to step out into the public and show themselves, not just as skeletons about to die but actually as people like you and I with a life force, with dreams, with history, with children, with family and with everything that, actually, every person could identify with.

Code 1 NHM – HM Materials catalysing complex conversations (with the self). **Validates participant experience. E**

I think the overall aim would be for participants to gain or deepen their trust in themselves, ultimately, and also in their... Trust but, maybe, also somehow befriend their bodily being in some ways but I think, especially when there's a lot of suffering and a lot of pain and a lot of bad prognosis, somehow also finding something that is liveable and alive and validating that and trusting that, whatever that might mean. Even if people die, what within their being feels precious and alive. I think to really trust that and to give that a form and shape and to share that with others, whether that's in the workshops or whether people choose to take that beyond it. That doesn't deny... There's plenty of space as well to share the suffering but I think, ultimately, the aim would be to take something out that feels valid and alive.

Code 1 NHM-HM Materials catalysing complex conversations. **Elicits curiosity. Forms a different view of health. Accesses people's stories. E**

Even afterwards when people present, like in the context of Kenya, when people took the step to have their body maps in the public domain, very often they would be there as well and it's usually either the colour or the shape of the nature of their body map, that would be the starting point of a conversation about the body map. Again, I think it just elicits curiosity. It elicits a less preconceived conversation possibly, especially with people who spend part of their lives in a medical context or environment where they're being diagnosed or analysed. Certain things mean that, this is good, this is bad, this dangerous, this is healing or whatever. People have a very medical map of their body that is very strongly defined and so I think the material nature of the maps allows the breaking out of these life-limiting definitions.

CODE 2

Code 2 NHM-HM Self-selected objects enable participants to access unfamiliar experiences through the familiar. **Provide understanding of intimate experiences. E**

The ritual of selection. What represents a life? What represents a person? What I liked about it, I think 90% of the objects are entirely ordinary objects. If you walked into a thrift store or a charity shop or any kid's bedroom, you'd see them. I think their strength is their ordinariness. They're just so ordinary yet the same people pick them up and closely examine and look for tears.

Code 2 HM – NHM Self-selected objects enabling participants to access un/familiar experiences. **Connect to bodily experiences. E**

I always invite people as well to bring something. If there is something that they would really like to work with, a particular art material or a particular natural material, I really encourage them to bring it with them. Sometimes people pick something up on the way to the studio or sometimes they've had something sitting in their cupboard for decades and they've been dying to do something with it and they finally have an opportunity to put it on their map. It really depends. I'm very happy for people to bring and to be really creative with it as well. There's really no limit as to how you use that map, whether you stitch something or sew on or whether you cut through and you weave something through it, whether you sculpt something onto it or whether you layer it. There is no limit to the creative way as long as it has a connection with what your body's experiencing.

Code 2 NHM-HM Self-selected objects enable participants to access un/familiar experiences. **Deflects from difficult subject matter. Brings participant thoughts and feelings into public realm. Sets the agenda for conversations. E**

One is at the very beginning of the workshops, when the group comes together and people don't know each other yet. I often ask people to bring an object. Also, in preparation to my workshops, my booking forms include a number of questions and I make people aware that, by answering those questions, they are already starting the body mapping process so it's reflective. Those questions relate to things in their lives. They relate to cyclical awareness, whether that's in their body, menstrual

awareness, cyclical awareness or seasonal awareness. I think those are the key questions because I have a theme that is seasonal as well. I ask people to bring an object that's not directly linked... It depends. When I worked with people with HIV/AIDS, we asked directly what supports them in living with HIV/AIDS and they would bring an object with that. Now I bring in more seasonal and ask them to track their bodily being leading up to the workshop and then bring an object that represents something in that. It's up to them what they bring but it really helps to share something. You have a transitional object so the focus is not necessarily on you but it's on what you bring. It's something that often people pass it around so there's immediately an experience that people can touch and have their own experience of it. You can talk about something in relationship to yourself and it often feels less exposing and, at the same time, it's more interesting than, "I live here and I do this and I'm a professional whatever." It cuts underneath the persona that you bring. You bring something small that people can relate to, possibly.

Code 2 NHM-HM Self-selected objects enable participants to access un/familiar experiences. Deflects from difficult subject matter. Enhances possibility for intimacy. Brings participant feelings into public realm. E.

I think why it works is because people often find it easier to first talk about something that's outside of themselves rather than directly about themselves. It helps as a focus and a slightly external focus that you can then link with personal material. It helps in approaching yourself within yourself but also in your relationship with others more gradually. It also works because objects are always multidimensional so they hold surprises. You can play more easily with something than with yourself. Like in the example before, it's something you might be happy to share and for others to hold and touch and give more meaning to rather than being touched and made contact with directly. Again, it's this in-between thing that has much more freedom as well as also maybe more possibility for intimacy at a particular stage of the body mapping process. It's just much more fun, I think. It invites creativity as well. I can't think of any more reasons for it. By the invitation to find something, people have to go out and search and think about it. It already invites a curiosity or maybe going beyond the normal pattern of doing things. That's the same for the way you share it. It might be not the usual way of how you present yourself to others.

Code 2 NHM-HM Self-selected objects enable participants to access un/familiar experiences. Deflection from difficult subject matter. E.

Sorry. I'm not explaining this very well. When I started mending I would invite people to bring me things. I was always really interested in repair as a way to start a conversation with someone. That's it's easier to talk through a garment to a stranger than it is to talk to them face to face. It's like when you go to a party. If you compliment someone on something they're wearing then you've got something real to talk about. Whereas sometimes it's harder to say, "How was your day?" Or it's less interesting. But if you say, "Oh, I love that colour," then you're off. "Oh, that's my favourite colour." For me anyway. So this was my idea. That if I asked to mend things for people...Partly, I'm nosy and I wanted to see other people's clothes, but I was just intrigued by an insight into the lives of others. So I was saying, "I have to..." The things people brought were invariably things that they really loved, and that's what made the work good. I wasn't a mending service. I wasn't a technician mending a pair of jeans that just needed fixing. Or I'm not a dry cleaners. Though I love a dry cleaners. That's not what's strong in the work. The strength is that the stuff that people bring is stuff that really matters to them. Then Richard spoke a little bit about how the value of encountering a real body for these 18-year-old, 19-year-old, medical, physio, dental, whoever students, was a slightly unquantifiable value, but it was one he felt really strongly was important.

Code 2 Self-selected objects enabling participants to access un/familiar experiences. Supports conversation. E.

But once they were bringing me their things, their home things, "Oh, you grew up in South Africa. That's interesting. How come you're over here? Why did you...? What are you hoping for by becoming a doctor? Can you imagine yourself in the role?" I don't know. Our conversations would just sort of free flow, but, "Is this difficult?" "Yes, it is difficult."

Code 2 NHM-HM Self-selected objects accessing un/familiar experiences. Provides understanding of intimate experience. E.

It felt like the thing about looking at their clothes is the invitation to talk about themselves. How their body moves. If they're heavy in their clothes. So it's more about their own body and their own self in their clothes.

Rhian Solomon: Did you find that there was a dialogue being opened up between yourself and them about the materiality of the body, or not?

Celia Pym: No, not so much. Well, I feel like the whole conversation was about the... We were constantly talking about anatomy. We were constantly talking about, "Oh, I saw this amazing gallbladder. This liver was extraordinary."

Or even the experience of looking inside the body we were talking about. It's really hard to imagine the space inside the body. Yes, we were talking about material like that, but that's what they were studying as well. I think the conversation around the clothes, as we've touched on, was more about feeling. It was something more emotional. It's just harder to name the emotional experience of... It's just a whole other world. I think lots of people...

Code 2 NHM-HM Self-selected objects accessing un/familiar experiences. Provides understanding of intimate experience. E/C.

And the body and skin and our physical self is quite difficult to talk about. My point of view is start with the thing that you can talk about, which is the cloth, or that provokes some feeling. Even if it's a bit of a gross out feeling. It's like, "Okay, that's the place." If you provide it, if you come to a workshop with all this lovely material, it's pretty hard not to start talking about it. Or if you come with your garments...

Code 2 NHM-HM Self-selected objects accessing un/familiar experiences. Deflects from difficult subject matter. E.

Because the material of the clothing lets you talk about your body a lot of the time and talking about your body is quite tricky.

CODE 3

Code 3 HM – NHM Workshop participants crafting artefacts. Supports understanding of anatomy. E.

Yes, I think so. Well, with the first one, working with the textile-based materials, definitely, because I think, in general, people immediately see it as something that goes on the body. So I think automatically it creates this idea of a second layer of skin. I don't talk about it in a way, but it is a second layer, so by extension and thinking about the layer of pelvic floor muscles and the layer of skin, so thinking about all these different layers, I think it helps.

Code 3 HM – NHM Workshop participants crafting artefacts. Shapes an understanding of existing bodily knowledge. Enhances understanding of anatomy. E.

I asked them to think about the reproductive organs and draw the reproductive organs if they could on that piece of underwear, if they had an understanding of where it went. Maybe some of them were outside the underwear, as one of the girls mentioned, thinking about the position of the different organs in the body. Where do they go? What is it that they can sketch on that piece of fabric? It's just to get them started and also to understand what they know, what they don't know. That's also how you understand in a workshop setting that knowledge is actually quite limited. (Laughter). Then, the second activity was related to that. It was a new piece of underwear that had a little soft circuit, so the textile already prepared for them. It had a little soft circuit, and there was a screen print of all these different pelvic muscles. It was a flat pattern. They had to assemble it. When assembled, it would show the female perineum as a whole, but the design would show the muscles - so it's the layer underneath the skin - just to help visualise that what we have there is this bunch of different muscles that link together in some way in the way they connect to each other depending on how you move them. If you do the Kegel exercises, the pelvic floor muscle exercises, those muscles lift and you contract and relax, so it's trying to visualise that in some way.

It's very difficult to explain. It's very hard to visualise. There are different techniques that you can touch on your body, and you can feel the muscles contracting or relaxing. So it was a lot of new knowledge. With the e-textile, I tried to just have a very, very simple kind of... Not even interaction, but it was just like these little lights going up and down to simulate the contraction and relaxation.

Code 3 HM – NHM Workshop participants crafting artefacts. Dissolves embarrassment and catalyses stories. E/C.

Yes. Yes, so just that confusion and then the idea of talking about these different parts of the body, and cutting and assembling and looking at the visuals. Of course, the visuals... They have a vagina or they have an anus and all those different recognisable parts that make people really embarrassed, and at the same also laugh and tell stories. So that was quite interesting, yes.

Code 3 HM-NHM Workshop participants crafting artefacts. Facilitates bodily introspection. E.

Well, I think from that one workshop and also from the work I did afterwards, this idea of embodied knowledge is quite appealing to me. I like the idea of designing for embodied knowledge – the difference between designing an application on a mobile phone or designing a mobile application that works only if you look at your body, which is the other study I did. I think that somehow, as awkward as it might sound or feel while doing it, just the act of physically having to look at some body part or looking back at your body other than just looking at a screen on your phone, that already prints something on you. I think it's more memorable. I think, if nothing else, it makes you ask more questions and really look on the body, not just on something you have when you're at home.

Code 3 HM-NHM Workshop participants crafting artefacts. Facilitates bodily introspection. Engages participants with past experience. E/C

I include a lot of awareness of prenatal development in my work because the process of a body map taking shape and, with that, a human being becoming visible on the map really resonates quite deeply with people's original experience of becoming a body and coming into the world. That's what I've realised over the time and so I've done a lot of extra research and training and on-going learning in how we embody this resonance in our daily life and really tune quite finely into that, especially at the moment of people stepping onto a blank canvas and that whole process of finding a place and finding a shape and being traced, which is what gives the map the form, the human form.

Code 3 HM – NHM Workshop Participants crafting artefacts. Facilitates self-care. E

In the course of the workshop, she then used moss to put on her body map to create more and more softness and something that she could not just make a body map soft but, even when she contacted her body map, her own body would then contact and feel something soft. I think, at some point, she would lie on her body map as well and then feel the softness that she had given her own body on the map. It becomes a very multi-layered relationship between the body that we live in and the body on the map but, really, the moss allowed her to explore softness and then resting into softness and, with that, recuperating and resourcing herself whereas, initially, that was a barely visible or experienceable for herself.

Code 3 HM - NHM Workshop participants crafting artefacts. Supports understanding of anatomy following procedure. E.

On reflection of the workshop, one woman said that seeing the 3D version of a nipple as opposed to 2D images had helped her understand the procedure, and had informed her of, exactly, how a reconstructed nipple is made.

Code 3 HM - NHM Workshop participants crafting artefacts. Supports decision making on type and permanence of nipples. E.

On reflection of the workshop..one woman said that it had helped her to make decisions on permanent nipples and what type she wants.

Code 3 HM - NHM Workshop participants crafting artefacts. Supports patient to find closure on her cancer experience. E.

On reflection of the workshop..Another stated that the session had helped her with closure to the cancer diagnosis, treatment and recovery process.

Code 3 HM - NHM Workshop participants crafting artefacts. Shapes knowledge to impart to other patients. E.

On reflection of the workshop.. one said that it provided her with knowledge to impart to others, should they also be interested in undergoing this procedure.

APPENDIX F.3. PHASE 2 ANALYTICAL APPROACH

APPENDIX F.3.1. WARDROBE PROBE DATA

Participant 2			
Worn item	Description	Significant moment	Significance of item
1	Pink shoes	Wedding day 2 years before diagnosis The 'for worse' came way too soon.	Grateful to G. A. for sticking by me. The favourite part of my wedding outfit - resisting the traditional.
2	The black and white jacket. (second hand via mums giving table)	Working too hard and right through the biopsy > diagnosis window was 'on duty'. If not this jacket, another one was worn to a meeting and dinner the night before diagnosis day.	I used to put this on to 'feel the part' and look smart. I now feel more confident as me at work and this is just appropriate clothing as and when needed but less a part I'm playing.
3	Floral dress.	I remember wearing this again, 4 months after my op when I went to a festival with two friends. I felt joyful, dancing and laughing and embracing the moment. To have made it there. But also remember feeling nervous in case anyone saw my chest as I changed in the tent.	This dress came from a second hand clothes market in (Nairobi?). I wore it with a pink headscarf and shawl when I worked in (Somaliland?). The pattern made me happy. When I returned, I cut it off and wore it to festivals. It is a connection to the me who worked for 20 months in the desert - another time in my life - but also friendship.
4	Check pyjamas.	I bought these in Hammersmith TK Maxx when I was lacking time between diagnostic tests. I wasn't allowed to eat or drink. Had some kind of needle in my arm. I didn't quite know what was coming but already knew an operation was on the cards. And so Pyjamas seemed a thing I would need in uncertain times.	A helpful reminder that there were fewer pyjama days than I'd feared there would be. And of a time when sleep and naps came easily - Before the ***** Tamoxifen. These have been camping since, so no longer the 'sick' person PJ's.
5	Maroon sports bra.	Recovery at home, once the massive bruises/swelling subsided. Still have them as still have one more tattoo to get through.	Memories of an awful bra fitting experience at M&S. Turns out, they weren't very good sports bras when I started running in them - they rub too much.
6	Navy jumpsuit.	The 'bridesmaid' outfit that a sports bra and support knickers would go underneath. - 2 months after surgery (dress code navy and pink) and much deliberated over as I tried to find 'the thing to wear'.	I wore this with a pink hat to my friend's wedding. It was a great day. I still felt like a bedraggled, eagle and in the pictures I can see I was quite thin and tired. But I felt elegant, like I'd made an effort and comfortable to be photographed.
7	Paint splash blouse.	The baggy enough and dense enough fabric blouse but not too frumpy 'go to' for the Summer I went back to work. As a shape that didn't require cleavage but feels distinctive and not shying away/hiding away!	I bought it on a shopping trip with a friend and it felt good to buy something for the 'after' and to celebrate with xx after by (illegible) time with C in Winchester.
8	Green Hexagon coloured dress.	I wore this to go out with friends after lock down and it's also been to The Chelsea Flower Show and a posh birthday doo. I like wearing it as I get compliments on it. I feel it fits well, it's	I got the fabric from a fabric shop I went to with a friend between bouts of chemo. I made this using learning from sewing classes I did during treatment and it's made to fit my new body. I

Commented [MOU5]: Code 1 Supports understanding of networks of care. NHM-HM Garments reminding participants of people and activities together - Provides understanding of people and networks surrounding them (for researcher). (E).

Commented [MOU6]: Code 12 Changes perspectives of wardrobes. HM-NHM Participants mapping the wardrobe - provides new perception of clothes, now. (E).

Commented [MOU7]: Code 9 Supports recognition of progress. HM-NHM Participants selecting worn items - recognising progress. (E).

Commented [MOU8]: Code 16 Supports understanding of intimate experience. HM-NHM Participants selecting bras - supports reflection on experiences of recovery. (C).

Commented [MOU9]: Code 1 Supports understanding of networks of care. NHM-HM Garments reminding participants of people and activities together - Provides understanding for the researcher of people and networks surrounding them. (E)

Commented [MOU10]: Code 1 Supports understanding of networks of care. NHM-HM Garments reminding participants of people and activities together - Provides understanding for the researcher of people and networks surrounding them. (E).

APPENDIX F.3.2. WARDROBE PROBE FEEDBACK FORM

1. How did you find doing these exercises? (Wardrobe Mapping - Participants selected 9 worn items from their wardrobe - 3 that represent pre, 3 during and 3 post treatment. They then completed a hanger for each item, asking them to consider how and why these items were significant to them.)	
P1	It took me a while to find items, not just physically, but emotionally. But it was really interesting to do this at a time when I am reconsidering my breast reconstruction.
P2	This took me a long time to get started (10 days after the zoom call) but I guess the 'selecting' had been playing through in my mind through all that time. Once I actually started pulling the items out of my wardrobe, choosing between a couple of things I found I was enjoying the process. And in particular I enjoyed the writing of the hanger stories. I am now looking forwards to the next exercise.
P3	I initially started this over a week ago. I then found excuses as to why I was too busy to complete the task. Once I started properly!! it was an enjoyable experience.
P4	It seemed to take me a long time to select the items - I'm not sure if my pre diagnosis choices are too far in the past but hope ok. Maybe a time frame for the items e.g. 5 years before. I have enjoyed looking at what's in the wardrobe and have re-discovered some old favourites.
P5	Difficult at first. It took a while to think of items (especially pre-diagnosis) but once started, I had actually, too many. I had thrown lots of things out over the pandemic to Spring clean and a lot of my clothes are at my mother's house since I returned to the UK. So perhaps there were items I'd been unable to access. I think it took longer than 1.5hrs but it might be because I'm getting used to doing these exercises?
P6	It took me a long time to sort out which items to include and made me feel quite mentally tired.
2. What did you enjoy most about these exercises?	
P1	Realising how much significance so many items of clothing/jewellery have.
P2	-Writing the hanger stories. -Being able to put some items aside 'They weren't the most important story' - particularly liberating for the chemo scarves! -Enjoying the 'now' garments and stories with them. And that they show celebrations and friendships and people, but also noticing that before stories involved (illegible) stories too.
P3	I found it difficult to find three items in my wardrobe from 5 years ago. I felt happy as I progressed to my newest items as I know I am at my happiest now I have had my 5 year scans. I feel my clothes have become more vibrant.
P4	It prompted a big wardrobe sort, which has been really helpful. I've found clothing that I'd forgotten about, tried things on and thrown some stuff away which I'd been hanging on to but not wearing.
P5	Thinking and writing about the significance of the item and it's symbolism - it had a therapeutic dimension.
P6	Reviewing my more current pieces, which made me happy.

Commented [MOU1]: Code 5 Raises complex emotions. HM-NHM Participants mapping the wardrobe - Raised complex emotions/avoidance. (C/E)

Commented [MOU2]: Code 11 Changes perspectives of wardrobes. HM-NHM Participants completing the probe - created new perspectives of the wardrobe. (E).

Commented [MOU3]: Code 6 Raises positive emotions. HM-NHM Participants mapping the wardrobe - raised positive emotions, created new perspectives of the wardrobe. (E).

Commented [MOU4]: Code 11 Changes perspectives of wardrobe. HM-NHM Participants mapping wardrobe - prompted new perspectives of the wardrobe, culling of wardrobe. (E).

Commented [MOU5]: Code 11 Changes perspectives of wardrobes. HM-NHM Participants mapping the wardrobe - raised positive emotions. (E).

3. What did you enjoy least?	
P1	Taking photos. I took bad ones! Going to try again, as I know they are key.
P2	For the before garments, in particular, I found it difficult to decide between the 'significance to me' and the 'significance/where in the diagnosis process' questions. I found identifying the before outfits most challenging.
P3	It took me a while to find pieces from before cancer.
P4	Photographing the garments has been tricky due to the time of year - dark Winter days and low light levels.
P5	There was a slight melancholy about thinking of items from before or on the day of my diagnosis. I was a bit unsure how far back the 'before' was allowed. I took it to mean pre diagnosis by years (Life in South Korea) so it wasn't necessarily one definitive moment.
P6	My indecision and second guessing myself.
(Do you have any recommendations for how the exercises can be improved?)	
P1	No content
P2	But that may also be a reflection of doing this exercise two and a half years on - so some of the stories/memories are less relevant and, well, because of Covid - how many of the stories from then to now in my wardrobe are because of that instead?
P3	No content
P4	No content
P5	No content
P6	I think having the extra week is helpful to spread things out a bit.
4. What are your thoughts on the concept for these exercises?	
P1	I think it's a great idea as I didn't realise how much of my life is wrapped up in what I put my body in or on. I like the design of the hangers and the questions and discovering things as I wrote.
P2	Noticing that the chemo journey is quite enmeshed with the reconstruction journey for me, but for this exercise I focused most on associations with my body rather than how. I think this is a helpful way of recollecting occasions and moments before, during and after. The 'narrow it down to 9' (items) is helpful but felt like a hurdle. Maybe some flexibility e.g. 2-4 to each time zone - max 10? Important to frame in 'uncover some of the story/see if there is a story'. Different garments pulled out would say different things - equally valid. However, just doing the exercise has shifted something today for me, so I feel that there is a benefit in it as an exercise.
P3	At first, the three 'before' items made me feel anxious. I never realised just how many clothes I got rid of after surgery. On reflection, it has been so helpful as I can see just how far I have come. I can see my clothing choices have become bolder and stronger and I like that about me.
P4	It's a good way of taking stock, the garments are a visual prompt and trigger details of events that have been forgotten. It has made me reflect on how I approach things/manage difficult times.

Commented [MOU6]: Code 5 Raises complex emotions. HM-NHM Participants mapping the wardrobe - raising complex emotions. (C).

Commented [MOU7]: Code 11 Changes perspectives of wardrobe. HM-NHM Participants mapping the wardrobe - provides new perception of clothes, now. (E).

Commented [MOU8]: Code 18 Processes emotions. HM-NHM Participants mapping garments - creating emotional shift/change. (E).

Commented [MOU9]: Code 5 Raises complex emotions. Code 2 Shapes recognition of resilience. Code 9 Shapes recognition of progress. HM-NHM Participants documenting changes to wardrobe - raising complex emotions, helps them to recognise their role in recovery/resilience. (C/E).

Commented [MOU10]: Code 10 Situates experience. HM-NHM Participants mapping wardrobe - supported p's to consider individual moments, details, but also 'taking stock'. (E).

APPENDIX F.3.3. WARDROBE PROBE FOCUS GROUP

01:14:05.550 --> 01:14:10.040

Participant 3

I think with the UM, the front and the back of the garment..(Activity 3 - collage)

01:14:11.120 --> 01:14:23.120

Participant 3

Uh, so my son happened to be home on the day I was doing the collage and I see the back being very very different to the front but.

01:14:23.680 --> 01:14:25.260

Participant 3

For me to be able to say to him

01:14:26.000 --> 01:14:55.580

Participant 3

'cause we, we'd actually been to the Saatchi Gallery a couple of weeks ago and we were looking at these.. thinking 'why would people put that? Why is that there? I don't understand what does this mean', and then suddenly I've created something that in my head makes so much sense, but someone else looking at it..so he's like 'mum, what have you put? What does it mean?' And I'm like, 'well, this means this and this is this and this this' so it's like it was amazing to put all these different things.

01:14:56.050 --> 01:15:15.270

Participant 3

That really meant a story to me. It was unfolding on the back (collage) and then when I got to the front it was like oh, this is a really nice story on the front, but there was still a little element. I've put a little black bit on the front 'cause in the back of your mind, for me, there's always this little something.

01:15:15.860 --> 01:15:33.590

Participant 3

Uhm, but even within that it was like the front is such a happy place. But again I had to explain to him why, why it was my happy place and I think that maybe sometimes, like you say, even with your surgeon or whoever it may be, the Oncologist.

01:15:34.670 --> 01:15:46.100

Participant 3

Commented [MOU137]: Code 15 Facilitates self-expression. NHM-HM Crafted artefacts support communication with family members - support participant self expression. (E).

APPENDIX F.3.4. WARDROBE PROBE GROUP WORKSHOP



Commented [MOU3]: Code 22 Combines participant experiences/perspectives. HM-NHM Participants creating garment map - consolidates/documents multiple perspectives (service user, clinician, designers), fosters empathy. (E).

Commented [MOU4]: Code 26 Removes established roles of healthcare. HM-NHM Participants wearing own clothing for workshop. Removes established roles. (E).

APPENDIX F.3.5. WARDROBE PROBE GROUP WORKSHOP FEEDBACK FORM

Activity 4 - Constructing the garment	
P10	No. The garment seemed pre constructed as in already sorted how they fit together. Wasn't sure how the garment part linked to the day. Not sure how the garment will actually come about – the ones you had – you had already decided on their shape – moreover the placement of the headings we wrote on them – as in the group did not decide on the weight of the importance of the headings e.g. challenges and decide that could go to the back of the garment or that's the front.
P11	Having to work as a team to make something tangible gave a sense of comradery and positive shared experience.
P12	Yes. I found it to be useful as it felt more of a collaboration with each other, because it was hands on, quick, and you could see a product at the end, which felt like you had achieved something rather than just concepts. It really bought everyone together in a different way.
2. How did you find working with service users/designers in this context?	
P10	Good.
P11	Great! The different emphasis and viewpoints were helpful to give a 'full circle' view.
P12	I loved working with the patients and designers. I am very used to working with patients and found it really exciting to be with service designers and researchers as they have such a different mind-set that was thoroughly refreshing and exciting, like actually things can be changed for the better whilst we have people like JS working as a service designer.
3. What worked well during today's workshop? And why?	
P10	Space Large organisation Looking after/treating with respect as in refreshments etc
P11	All of it! There was enough to focus on to have conversations but enough space to allow those to develop organically
P12	I found the circular seating, the small tasks, the openness of the conversation all worked really well, because it kept everyone together, there was no one leading or being able to hide and it felt practical and engaging without any pressure.

Commented [MOU157]: Code 23 Connects participants. HM-HM Participants working together (to make coat) - enhanced sense of friendliness, familiarity within group. Connected participants. (E).

Commented [MOU158]: Code 23 Connects participants. HM-HM Participants working together (to create coat) - enhanced collaboration, created sense of achievement, connected participants. (E).

APPENDIX F.3.6. PHASE 2 COLLATION OF DATA OUTPUTS

Code 1 HM – NHM Participants selecting worn items - Supports understanding of networks of care

<i>Pink shoes</i>	<i>Wedding day 2 years before diagnosis The 'for worse' came way too soon.</i>	<i>Grateful to G. A. for sticking by me. The favourite part of my wedding outfit - resisting the traditional.</i>
<i>Navy jumpsuit.</i>	<i>The 'bridesmaid' outfit that a sports bra and support knickers would go underneath. - 2 months after surgery (dress code navy and pink) and much deliberated over as I tried to find 'the thing to wear'.</i>	<i>I wore this with a pink hat to my friend's wedding. It was a great day. I still felt like a bedraggled, eagle and in the pictures I can see I was quite thin and tired. But I felt elegant, like I'd made an effort and comfortable to be photographed.</i>
<i>Paint splash blouse.</i>	<i>The baggy enough and dense enough fabric blouse but not too frumpy 'go to' for the Summer I went back to work. As a shape that didn't require cleavage but feels distinctive and not shying away/hiding away!</i>	<i>I bought it on a shopping trip with a friend and it felt good to buy something for the 'after' and to celebrate with xx after by (illegible) time with C in Winchester.</i>
<i>Green Hexagon coloured dress.</i>	<i>I wore this to go out with friends after lock down and it's also been to The Chelsea Flower Show and a posh birthday doo. I like wearing it as I get compliments on it. I feel it fits well, it's my style and it takes me to joyful places and company.</i>	<i>I got the fabric from a fabric shop I went to with a friend between bouts of chemo. I made this using learning from sewing classes I did during treatment and it's made to fit my new body. I shared this with a sewing community focused on post-surgery fitting. Enjoying being a Sewist.</i>
<i>Cream, black and brown round neck blouse to be worn over black vest top.</i>	<i>This blouse makes me think of a warm Summer, being with my husband and children on holiday.</i>	<i>This blouse reminds me of a happy holiday when I had no idea what was ahead of me.</i>
<i>Patterned, red and burgundy dress.</i>	<i>This dress was bought looking at the future. I had now had 5 surgeries. My head was very positive and I felt secure in myself.</i>	<i>I wore this dress when I went to a lovely restaurant. I have worn it quite a few times. Also to my sons' graduation. It makes me feel positive.</i>

<i>Wrap dress. Blue with orange pattern.</i>	<i>This dress is by a woman who really gets women's body shapes. I feel good in it. The material falls so well. It is significant that I feel confident to wear a wrap dress.</i>	<i>This dress sits very well across my chest. My eye is drawn to the pattern and not my chest.</i>
<i>White short PJ's.</i>	<i>Bought to go into hospital for the DIEP reconstruction. Through a mutual friend I met someone who had experienced the same operation, she helped me understand the recovery process and to prepare well. These were the lightest, front fastening PJ's I could find - quite pretty and feminine.</i>	<i>Fiona was kind enough to give her time and share her experience with me - a relative stranger at the time. I lived in these PJ's after the op - the cotton was really soft and cool. They didn't look obviously like PJ's - I used to walk around the garden for exercise while recovering.</i>
<i>Beige tummy control pants.</i>	<i>These were recommended by the plastic surgeon for wearing for 6 weeks after the op. I was horrified at the thought of Lycra day and night as I was so hot (perimenopausal). I was ticking off the weeks so I could take them off. It was a significant point in the post-op recovery.</i>	<i>They were strangely comforting and I missed how comfortable they were when I went back to normal pants. Finding underwear that doesn't rub, scratch the scar was a challenge.</i>
<i>Grey wool coat.</i>	<i>My first new Winter coat for some time. Worn to a Christmas get together with old work friends who I hadn't seen for a while and found out about my cancer after the surgery.</i>	<i>Bought to celebrate being discharged from breast cancer unit. Still with the plastics team but this was a big step.</i>
<i>Khaki/brown T-shirt with abstract picture/scene from film - Jennifer's Body</i>	<i>My husband bought this for me this year as a birthday present. Even though I was still in the final part of treatment it felt like part of my recovery because it was during oral chemo, which was preventative medication.</i>	<i>It signifies my relationship with my husband which was further strengthened by my illness and brought us even closer together. It references a horror film I love and demonstrates how he understands me. I also started a film blog during convalescence and wore the T-shirt to a meet up of like-minded horror film fans/writers a couple of months ago which represented the pursuit of creativity (P.T.O) and something I wouldn't have done unless I had been unwell and thus had the time because I wasn't at work.</i>
<i>Light grey, chiffon, cocktail dress.</i>	<i>Evenings out with friends and family.</i>	<i>Represents a more active, social life. Now much diminished.</i>

<i>Black chiffon dress with stars and shooting stars in white.</i>	<i>My daughter bought this for me for Christmas. I was waiting over the Christmas period for results of an FNB (Fine Needle Biopsy), prior to my final diagnosis in January 2019.</i>	<i>It represents a period of anxiety but still a period of hope that there was nothing wrong.</i>
<i>Grey fitted dress with black rose pattern.</i>	<i>My daughter encouraged me to buy it soon after surgery. I really didn't think it would fit or suit me but was surprised when it did.</i>	<i>The first piece I bought for the new me.</i>
<i>Bright red, cotton, Voile dress with white polka dots. Fit and flare.</i>	<i>Went dress shopping with two friends to 'bombshell' looking for a dress for my daughter's wedding. I didn't find a dress for the wedding but tried this on and had to have it.</i>	<i>It's vibrant and there's no way you won't be noticed. It really suits my figure.</i>
<i>'Underwired bras'</i>	<i>'On advice of surgeon'</i>	
<i>'Button through PJ tops (made by mum for post-surgery)'</i>	<i>'Served purpose immediately post-surgery - didn't want the reminder - have other reminders of mum's crafting skills.'</i>	

'Again, some of the garments have stories of me in relation to others. I've enjoyed feeling gratitude for the people in my life. E.g. The friend who made the emergency run to M&S as no-one told me about post-surgery bruising and I had the wrong size bra.

Participant 2

I think something that came up for me was.

00:12:19.100 --> 00:12:50.880

Participant 2

lots of the clothes during and after remind me of people and say like one of the things was what I had to wear to be a bridesmaid. Like soon after surgery but that was also kind of a celebration of I was at a wedding that I might not have been at. So I think I think for me although the clothes were the hook the story it told for me was a bit about.

00:12:51.210 --> 00:12:59.460

Participant 2

People being there with me and and the kind of looking at the things last feeling.

Code 2 HM-NHM Participants documenting changes to the Wardrobe/crafting collages - Shapes recognition of resilience

'At first, the three 'before' items made me feel anxious. I never realised just how many clothes I got rid of after surgery. On reflection, it has been so helpful as I can see just how far I have come. I can see my clothing choices have become bolder and stronger and I like that about me.'

'Realising that the 'in treatment clothes' don't make me upset and I now see them as armour for an experience I'm glad and proud of being the other side of. I would not have registered this without this exercise. And I didn't feel this way at the time I bought or first wore them.'

'Once I had placed all the garments together I realised how colourful I now like my clothes to be. Allowing my head to go back to a very scary time has been ok. When you have a mastectomy it is always with you. Every time I take my clothes off I see it. By doing this exercise, I can see my progress of healing both physically and mentally.'

'I'm proud of how well I've coped with it all. It's made me take stock and look at the many stages I've gone through to get to here. Some issues still need work but I'm still waiting for (nipple reconstruction) surgery - once it's all finished, hopefully I can move on.'

Code 3 HM-NHM Participants working with worn/discarded items - Supports understanding of self-care practices

<i>Silver drop earrings.</i>	<i>I bought these with chemo baldness in mind. I was aiming for glamorous Joan Collins, South of France, circa 1970's. There is a photo of me in a head covering with these earrings in early Chemo.</i>	<i>I love these earrings. They are so dramatic and represent a time when I was looking at how to make the most of the physical changes to come.</i>
<i>Loose neck, polo neck jumper with sparkle.</i>	<i>I bought this jumper just before I was told I needed a mastectomy.</i>	<i>It was my go to comfort jumper after surgery. It is still a comfort piece of clothing now.</i>
<i>Blue, high, round neck jumper.</i>	<i>I purchased this jumper just before I was told I needed a mastectomy.</i>	<i>I wore this jumper a lot after surgery. It was a comfort blanket to me.</i>
<i>Colourful shirt dress.</i>	<i>Covid restrictions lifting. This Summer, seeing friends. This dress makes me feel optimistic. The dress receives a lot of positive attention. People like it. It makes me and others smile.</i>	<i>This style of dress detracts from the fact my breasts are different sizes. I know it makes me feel comfortable. I know I need more surgery and this style will always fit me. It gives me confidence.</i>

<i>Leopard print, packable rain coat.</i>	<i>Recovery impulse buy. I was unsure about this and decided eventually to buy it. Fun, quirky for me - I'd normally play safe with black/navy. It's my all weather emergency raincoat for when it rains and I'm out walking.</i>	<i>I started walking for fitness in 2016 and really enjoy the fresh air and exercise. It's me time, a chance to catch up with friends or go for a solo walk. The right clothes, no matter what weather, make all the difference.</i>
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<i>Black, Nike work-out top (Sports bra)</i>	<i>After my diagnosis and just before my chemo treatment started I resolved to get as fit as possible and joined the gym and bought work out gear for the first time.</i>	<i>Firstly, it was my first time buying gym clothes (I was fairly anti-gym before this! Haha!). And I actually enjoyed going. It was also my attempt to help myself before chemo and appreciate my body which I knew would change and it would be difficult to be so physical for a long time.</i>
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<i>Black and white polka dot pyjama bottoms with pink velvet tie.</i>	<i>I wore these continuously throughout my treatment because I spent a lot of time in doors (chemo and pandemic) in bed.</i>	<i>It signifies one of the roughest periods of my treatment - deep in the chemo, pandemic raging around me - trying to find simple pleasures and comfort. But I still thought they were fashionable and very me - so the illness didn't take all of my identity.</i>
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'I've used new clothes as a reward during my treatment to mark milestones and it has made me feel better - well given a temporary mood boost at least. I hadn't thought about the period between diagnosis and the main operation - I feel proud of myself for how I coped with all the tests and the wait for surgery.'

Participant discarded...	Because..	Participant discarded...	Because..
P2		P4	
<i>'Woolly hats from chemo'</i>	<i>'Reminded me of feeling nauseous after treatment'</i>	<i>'Bras'</i>	<i>'Wrong size, scratchy.'</i>
<i>'Underwired bras'</i>	<i>'On advice of surgeon'</i>	<i>'Knickers'</i>	<i>'Scratchy fabric.'</i>
<i>'Sports bras used immediately post reconstruction'</i>	<i>'Too big now (accommodated swelling). Was underwired and felt related to the pre me.'</i>	<i>'Trousers'</i>	<i>'Wardrobe purge/too big.'</i>
<i>'Pyjamas that were white/translucent'</i>	<i>'Mostly used for modesty when away - nervous lack of nipples would be seen.'</i>	<i>'Long black boots'</i>	<i>'Replaced.'</i>

<i>'Button through PJ tops (made by mum for post-surgery)'</i>	<i>'Served purpose immediately post-surgery - didn't want the reminder - have other reminders of mum's crafting skills.'</i>	<i>'Support knickers'</i>	<i>'Hated wearing these'</i>
<i>'Blue/white V-neck sundress'</i>	<i>'Felt too 'busty' immediately after surgery and too 'Boden' for my current style.'</i>	P5	
<i>'The 'chemo' cardigan'</i>	<i>'Served it's purpose - kept me warm during treatment. Never wanted to see it again!!'</i>	<i>'Multiple T-shirts'</i>	<i>'Old, wasn't wearing.'</i>
<i>'My wedding dress'</i>	<i>'Mum storing for me. Her suggestion. Decision to be made but feels less emotive than the things above'</i>	<i>'Dresses (for work)'</i>	<i>'Too frumpy, wasn't wearing.'</i>
P3		P6	
<i>'Dresses – numerous'</i>	<i>'Top fitted too much'</i>	<i>'Scarves'</i>	<i>'Had way too many.'</i>
<i>'T-shirts – numerous'</i>	<i>'Cling to my chest'</i>	<i>'T-shirts'</i>	<i>'Baggy.'</i>
<i>'Swimwear'</i>	<i>'My breasts look too different so purchased new swimwear.'</i>	<i>'Trousers'</i>	<i>'Old.'</i>
		<i>'Shoes (many heels)'</i>	<i>'Uncomfortable.'</i>