

A CO-CURATED EXPLORATION OF BREAST CANCER SURGERY

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X

FUTURE DREAMS
FOR THOSE TOUCHED BY BREAST CANCER

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Foreword

Our team at the Binks Hub at the University of Edinburgh specialises in conducting community-driven participatory research which uses artistic and creative methods and practices. Co-curation-as-research has become one of the methods that we use most frequently, but we were not the first, and are far from the only, researchers to work in this mode. Amongst creative methods that social researchers use it is particularly time and energy-consuming, and also tends to be emotionally-intensive. For this reason it is particularly demanding for emerging researchers conducting their Doctoral projects to engage with. This is just one of the many factors that makes Frankie Vale's 'Empowered Journeys' project so very impressive and important.

I first encountered Frankie and 'Empowered Journeys' at a participatory research showcase hosted by our mutual friend and collaborator Nel Coleman at the University of Edinburgh in June 2024. Frankie delivered a presentation about the project and facilitated a co-curation taster workshop, and it was in the conversation we had subsequently that the seed was planted for our collaboration. This seed grew into our conceptualisation, design and delivery of a two-day 'Utopia Lab' at the Edinburgh Futures Institute in November 2024, and has continued into the ongoing work of the 'Empowered Journeys' project following its launch exhibition in London in March 2025.

From London it travelled to Edinburgh to be shared with the University of Edinburgh community in partnership with university's main library in the exhibition 'Empowered Journeys x Outwith: Representations of Breast Cancer Surgery', and we were delighted to be invited to participate in the event that accompanied it. From there Frankie went on to join us in delivering a workshop on the research impact potential of exhibitions at the University of Edinburgh's 2025 Impact Festival, in which the 'Empowered Journeys' project was a key case study for participants.

We consider ourselves extremely fortunate to have been able to share in the wealth of knowledge accumulated by Frankie and her co-curators. Too frequently in academia it is assumed that the research conducted by PhD students is only preparation for their later careers, an incomplete and inferior version of the work done by grizzled veterans like myself, but the cutting edge work in 'Empowered Journeys' comprehensively gives lie to this assumption.

Dr Jimmy Turner, Research Fellow The Binks Hub // The University of Edinburgh





Preface

Empowered Journeys extended the invitation to individuals who have undergone breast cancer surgery to create their own forms of representation, and display them in an exhibition, to allow new experiences and ways of living a breast cancer journey to become visible. Hopefully someone visiting the exhibition will resonate with the artworks on display, and leave feeling less alone than when they entered.

This project started as a response to a crisis of representation. When I first found out that I had the BRCA2 gene mutation, I knew that I would be opting for a mastectomy rather than living with increased risk. I immediately started searching for images that resonated with me from art, artworks that made me feel visible, that made me feel seen. Although these images existed, I had to search for them. I found the most representation on social media platforms like Instagram, as other people were trying to fill the gap of representation by experimenting with their own forms of image-making to assert their own existence and their own experience.

Any representation that I did find in the mainstream media or from medical sources was either hyper-medicalised, wrapped up in some sort of gruesome fascination to inspire shock in the viewer, or trapped within a matrix of martyrdom and heroism; the tragic-yet-inspirational image of a woman fighting back against her diagnosis, not allowing herself to be limited or even affected by her surgical outcomes.

The purpose here is not to suggest that these are not valid ways of coping with breast cancer surgery, but instead to highlight the fact that these forms of visibility are not representative of the entire community of individuals facing their own breast cancer journeys. In fact, these forms of representation, though inspirational for some, can be detrimental for others.

Existing representation constructs an image to aspire to, that can in turn invalidate the lived experience of anyone who is not managing to live up to it. These images also do not often account for the temporalities of illness, which create a certain duality; at one moment a person might be embodying that image of heroism, but in another moment, they may not feel able to be strong.

This project created a space for people to find a visual language that represented their experience, elaborated within a community of people who would be supportive and understanding. Within this space, crossovers and resonances developed, which emerge in the exhibition.

Frankie Vale, PhD Researcher The University of Glasgow



What is Empowered Journeys?

The Empowered Journeys collaboration began in April 2024, as part of a wider PhD project being undertaken by Frankie Vale at the University of Glasgow, considering the representation of breast cancer surgery in art. This is a co-curated project: at every stage it was produced by multiple co-curators through a collaborative process. The co-curators are Alexandra Perry, Elizabeth Lydiate, Frankie Vale, Katherine Baker, Mary Geraghty, Penny Wright, and Sarah Browne.

Through group discussions that took place in April and May 2024, co-curators decided on a programme of creative workshops, which they then took part in to produce the artworks and other materials on display here. The workshops were organised as follows:

- June: Bodycasting.
- July: Contextualising the Bodycasts.
- September: Creative Writing.
- October: Painting.
- November: Textiles and Mixed Media.

The bodycasting sessions considered bodily transformation as a result of surgery, creative writing and painting focused in on emotional journeys, and the mixed media session had a more open format to allow people to consider their journeys in a more general sense.

The purpose of this project was to generate new forms of representation and visibility from the perspective of people who have lived experience of breast cancer surgery. The works on display reflect the individual visual languages that emerge when people who have had surgery are invited to create the images that they want to present to the world, unburdened by the expectations and forms of representation that have been projected onto them by society, the media, and the medical establishment. The range and variety of responses on display here demonstrate a truly key takeaway from this exhibition: lived experience is individual and unique and should be understood as such. Acknowledging the uniqueness and individuality of each person's lived experience, even if there are shared aspects of this experience, allows us to build communities and provide support more effectively.

We invite you, no matter your experience, to consider these works, and encourage you to share your own vision for how you would like to be represented and made visible.



THE CO-CURATORS



Alexandra Perry - H.E.R. Bodywear

My journey with breast cancer completely changed the way I saw my body and the way I approached life. I felt too young. I felt grief for losing my breasts. I felt unattractive. After my own experience with all of my surgeries, I struggled to find underwear that supported my healing, made me feel comfortable, confident, and truly myself again. That's what led me to create H.E.R Bodywear—designed to Heal, Empower, and Revive women who, like me, have faced not only the physical element of breast Cancer surgery, but also the psychological and emotional challenges. Through my work, I want to give women back a sense of strength, femininity, and choice, because every survivor deserves to feel good in their own skin

Elizabeth Lydiate

Elizabeth Lydiate has a background in fine art and marketing. She works with creative people of all disciplines, helping them with the business side of their practice. She has a long history as an academic, and as a consultant assists mainly governmental clients in the development and delivery of education and training for the creative sector. With her many increasingly accomplished and distinguished international research graduates she is currently working on a book about the creative act.

The 'Empowered Journeys' doctoral research study addresses an area of great interest to her, and she has gained much insight as a result of participating in the research team and learning from the experience and responses of the researchers.

Frankie Vale

I am a PhD researcher at the University of Glasgow, and my PhD considers the representation of breast cancer surgery and the post-surgery body in art.

In 2020 I found out that I am a carrier of the BRCA2 mutation, and that my risk of breast cancer could reach a lifetime high of 85%.

In May 2023, I underwent a risk-reducing mastectomy with immediate reconstruction. I knew as soon as I found out about BRCA2 that I would opt for surgery. I could not cope with the uncertainty of having a scan every year, with the odds being that I would have to go through surgery and treatment anyway. Pre-surgery it felt like I had two grenades strapped to my chest, ticking away in the back of my mind and only I could hear it.

I know I am so fortunate to have had this surgery, and visually it's hard to tell that I am any different from anyone else. However, my chest is totally numb, and sometimes I get strange stabbing pains under my implants,. When I hug too hard, my implants feel as though they might burst. My armpits and parts of my upper arm have very altered sensation, which can get quite uncomfortable. My body has profoundly changed, so I have had to, too.

I feel so fortunate to have been part of Empowered Journeys. Spending focused time thinking about my own surgical experience has helped me in ways I truly hadn't expected.

Katherine Baker

I'm a Mum, wife, project manager, with lots of varied interests outside of work. I'm a busy person, but who isn't? I was very lucky to find and not ignore my breast cancer. Age 46 I spotted a bruise in a mirror during a bra fitting, then saw a small lump, and noticed my nipple was slightly puckered. Everything was back to normal by the following day, so I could have easily ignored it. In reality, I had 2 large lumps (DCIS).

I was so shocked, especially as there is no history of breast cancer in my family. My first thought was of death, till the surgeon and nurse convinced me this was treatable. In September 2023, the day my then 9-year-old went back to school, I went into hospital for 4 nights. I had a skin sparing, nipple sacrificing mastectomy, sentinel lymph node biopsy with an immediate DIEP flap reconstruction. They rebuilt my breast beautifully using fat from my stomach, reconnected using an artery they harvested from my groin. My belly button was given a new buttonhole higher up my abdomen, to compensate for the flesh they removed. Basically, they rebuilt my front from the groin up. The operation took 7.5 hours, with 3 months off work, recovering slowly, building back up. I couldn't stand up fully straight for about a week, and could only walk slowly in a straight line when I came home; desperately avoiding catching a cough, cold or tummy bug to not re-open my vast expanses of stitches. Fortunately, the cancer had not spread to my lymph nodes, or elsewhere so I didn't need radio or chemotherapy. I'm not on any hormone suppressing drugs either, as it was triple negative. I'm now having annual checks for the next 4 years (am one year clear already!). I still see a physio regularly and am excitedly waiting to get a 3D nipple tattoo. The medical teams were all simply amazing, as were family and friends. I am very grateful.

I however sought support through groups to help me process what I'd been through, but struggled to find a good fit. I helped others, or just felt a fraud as I had had a very different cancer journey.

The Empowered Journeys workshops with the incredible Frankie and Alice, in which we created these art pieces, were just what I needed. Everyone had very different experiences. It was a warm and friendly, safe space, which allowed us to talk, helped us to explore our bodies and minds as they are now, our feelings, emotions and just to reflect on what we'd been through and lost, and to start to look forward. All done indirectly, gently, through a variety of different art forms, which I loved even though I wouldn't say I had an artistic bone in my body. A very powerful and positive thing.

Mary Geraghty

I was juggling a busy career as a lawyer with family life when I found a large lump in my armpit whilst showering.

Six months of chemotherapy, surgery to remove my right breast and lymph nodes and radiotherapy followed. I was looking forward to emerging from treatment with a perfect pair of size B boobs but the ironic reality is that my body shape, small breast size and weight made a reconstruction impossible.

I have had to adjust to my new body – small on one side and flat on the other. Radiotherapy and surgery have left scarring, puckering and a lot of skin sensitivity. For a long time, I found it hard to do my breast checks – touching the area of my surgery brought back memories of my initial diagnosis. Swimming and exercise has helped me rebuild my strength and recover a body that is strong, confident and in my eyes, beautiful.

My experience of undergoing cancer treatment has given me a superpower – the simplest of things bring me such pleasure – a swim in the sea, the feeling of warm sunshine on my skin, an autumn leaf, a frost covered tree, a walk in the park, a giggle with a friend.

Penny Wright

The first time I noticed something in my breast, I didn't know what it was. It wasn't a lump, just a little patch that felt a bit different... and then I wasn't sure if there was anything there at all. Except the next time I checked it was still, sort of, there. My GP wasn't sure either. She sent me for a scan to be on the safe side.

I had a mammogram and they took me straight in for a double biopsy. They were interested in two areas next to each other. The biopsies were unexpected, and painful, I was on my own and went home feeling shaken. A few days later I got a call asking me to come back in. I knew then that I had cancer and a huge shock ran through my body.

I did indeed have two adjacent tumours.

One was a Grade 2 Invasive Ductal Carcinoma (15mm)
with associated low - intermediate grade Ductal Carcinoma In Situ (15mm)
The other, a Grade 2 Invasive Micropapillary Carcinoma (14mm)
with associated low - intermediate grade Ductal Carcinoma In Situ (27mm)
with vascular invasion present.

ER 8 /8 (estrogen receptivity)
PR 7 /8 (Progesterone receptivity)
HER2-

I had "wide local excision" surgery, (a lumpectomy), with a sentinel node biopsy, which returned positive, so I then had complete lymph node clearance, which severed nerves around my armpit. Because my cancers were hormonally treatable I didn't need chemotherapy. I had a five day course of Radiotherapy, and some Zometa infusions, to strengthen and help prevent recurrence in the bones.

I will have to take Aromatase Inhibitors to prevent recurrence for at least 10 years. I had trouble tolerating the side effects of the first two types available; Anastozole and Letrozole, and am now taking Exemestane with slightly less problem.

Sarah Browne

I was diagnosed with Stage 3 Triple Negative Breast Cancer in July 2023, at the age of 36.

My diagnosis came having initially gone to the GP with a small lump that I had found in my underarm whilst on holiday. I found it quite by accident whilst putting on suncream - some days it was there, other days it wasn't! Whilst at the breast clinic I had an ultrasound, some biopsies, and a mammogram, and as they said that they couldn't see anything on my mammogram, I was told to go back two weeks later just for confirmation. However, when I returned, I was told I had cancer – the most aggressive type of breast cancer at that, and the hardest to treat.

Unfortunately, the lump I had found was a cancer positive lymph node, so I had to wait to see how far it had spread. After an MRI scan, they discovered a large primary tumour with smaller satellite sites and multiple lymph nodes involved.

What was also unfortunate is that the hospital I began my treatment at ignored my pre-existing health conditions and allergies. This led to a catalogue of medical negligence issues and incredibly poor treatment. Their actions and lack of appropriate medical care directly caused PTSD, trauma, and Stevens-Johnson Syndrome (a life-threatening allergic reaction), where I was hospitalised in the HDU for many weeks, and they had to pause treatment for 9 weeks.

Having decided to change hospitals as I wanted to try and ensure I survived, my second hospital was much better! After 11 rounds of chemotherapy, we found out my cancer was non-responsive, so I went to surgery early, having a bilateral (double) goldilocks mastectomy with full lymph node removal (23 removed, 7 were cancer positive), as well as lymphovenous anastomosis surgery. I had a further 6 rounds of chemotherapy, which hospitalised me for a week at a time, and which made all my hair fall out. In total I had 17 rounds of chemotherapy, followed by 15 rounds of radiotherapy.

I was given the news that I was 'no evidence of disease' in January 2025. I still have many symptoms and side-effects, some of which will last forever, and I will need some further surgery, but hopefully I am through most of my cancer treatment.

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Bodycasting

These casts were made in June, and then worked on throughout the project. The bodycasting process used here was completed in the following stages:

- The area to be casted is prepared with petroleum jelly, to ensure that nothing gets stuck to the skin.
- Plaster bandages are soaked in water, and then laid in strips over the area to be casted.
- Once three or four layers of plaster bandages have been placed, the cast is left to dry on the body.
- When the cast is dry, it will start to separate from the skin, and can be taken off with ease, leaving a negative cast.
- To create a positive cast, which are the more solid casts on display, the negative cast gets filled with liquid plaster, which is then left to dry, and the negative cast can be removed to reveal a solid plaster artwork, called a positive cast.

The bodycasting sessions were focused around considering the body post-surgery, and all of the associations that went along with it. For many of us, the way we looked at our bodies, and the way we experienced being looked at, had changed completely after surgery. This was the same with how we experienced touch, due to changed sensation. The process of bodycasting engaged both of these senses, recontextualising them away from a medical setting, and instead placing them within an atmosphere of solidarity and empowerment. Our bodies became the artwork, rather than a faulty vessel.



Creative Writing

The creative writing displayed around the exhibition was written in September and was conceived with the emotional associations around surgery in mind. In this session, we used free writing based on word association, as well as Ekphrastic techniques to generate pieces of creative writing. Free writing involves jotting down whatever comes to mind, without thinking about it too much and without stopping. Ekphrastic writing is a literary technique which involves vividly describing images. Each co-curator brought an image that resonated with them and their journey to the session, and images were also provided in case anyone did not have one or wanted to try something different. We were asked to "enter" our image, either by imagining that we were transported into it, or by imagining that we were a person or creature in the image and speaking from their voice.

As you will be able to tell by reading and listening to the pieces of text that were written, these ways of engaging with images allow the author to tap into many different emotions and feelings as the text progresses. By bringing our own images, we were able to directly consider representation and the emotions we associate with feeling represented or, indeed, underrepresented.

'I have no energy for colour, I wrap myself in soft warm grey and it is quiet, calm, soothing, like old bathwater, like puddle water, like a cloudy sky, like the dull sea, like all the grey jumpers I buy over and over and wear over and over' Penny Through the tears it's hard to see the leaves and the fruit. Some days, it is as though the tree is not there at all. On others, it stands tall, leaf by leaf, branch by branch, surging into the sky in a way that is truly magnificent. For a long time the tree had gone completely. Or maybe it was there, just shrivelled and bare and out of sight. I couldn't tell you.' Frankie 'There is a sacred bond between humans and nature But sometimes that feeling of being all at sea Is because the circle skips a beat And shows you, its not quite complete.' Sarah Oh, you are Isis Wounded! You are the Goddess! Only, instead of breastfeeding your son, the god, you are holding the place where your breast used to be, and is no longer. I have not lost my breast, but I have lost myself, the self that inhabited that unwounded breast, in the 'wide excision' I have been excised, removed, carved out of my own skin.' 🖳 Penny 'So don't call my cancer treatment a journey It diminishes the hell that I have been through It as a chapter in my book of life Moving on from page to page Never forgotten, but hopeful for a better ending.' Sarah

Painting

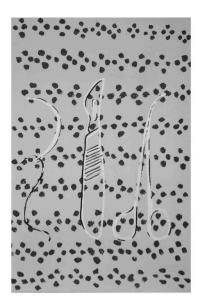
The painting workshop continued the exploration of emotional journeys. Some people chose to use their creative writing from the previous session as the inspiration for their paintings. Others elected to start on a painting based on new imagery that they wanted to explore. We were also given some prompts by the workshop facilitator, Alice, to help us think about the imagery and message that we wanted to get across. The prompts encouraged us to consider different types of imagery that resonated with our individual surgical journeys, such as:

- An object or collection of objects.
- A place, landscape, time of day, or weather pattern.
- A person, group of people, or a character from a book or a film.
- A colour or pattern.
- An animal, a cartoon character, or a mythological creature.
- A song or genre of music.

Alice also provided us with different styles of timelines to fill in to get us thinking about the way in which our journeys have developed over time. The purpose of all these prompts was to help us find a starting point for our paintings, that we could then work on over the course of the session.

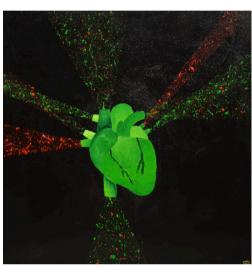




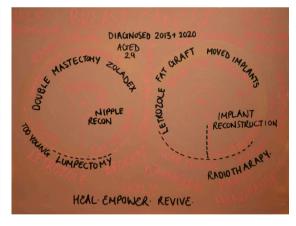






















Textiles, Found Objects and Mixed Media Collage

This workshop was an open session, where people could focus on any part of their journey that they did not feel they had explored yet, using any of the materials that were on offer, or that they had brought with them. Some prompts were provided, asking people to consider colours, textures, shapes, images etc. that they associate with their breast cancer surgery journey. Materials provided included canvases, paint, collage materials, embroidery materials, yarn, posca pens, and scrap fabric, among other options. Some co-curators even brought bras with them to embroider onto. Such a large range of materials and techniques accounts for the large range of artistic responses on display here.











Notes

These are additional themes as lenses through which to consider the artworks. In many cases the artworks were not crafted with these themes in mind, but instead they came up as threads that can be woven between the artworks.

Inspiration from Nature

Some of the pieces take inspiration from the natural world. So often we look to nature for its healing properties, and although some of the works displayed here associate natural imagery with healing, others acknowledge the duality of nature. They speak to the circle of life inherent within the natural world, a space that can be the source of both beauty and illness.

Duality

These artworks highlight the duality of the body following cancer surgery. They show that the body can be considered beautiful and should be celebrated for carrying a person through their illness. However, there is a dark side to the body, a feeling of threat and betrayal. The post-surgery body is the home for new sensations and pains, as well as for new realisations about the self and inner strength. The duality embodied by these artworks suggests that perhaps both sides can co-exist; rather than expecting people to return to "normal" life in a linear fashion after breast cancer, we should embrace both sides of them, and the non-linearity of healing.

Surgical Temporalities and Non-Linear Healing

There are different temporalities within illness and surgery: before, during, and after. Each of these temporalities brings its own challenges. You may not be aware of the before, until you have experienced the during or the after. Alternatively, the timeline of waiting for surgery when you know you need it may feel excruciating. The during may feel like a blur of medical machinery, hospitals, and appointments. Finally, the after, for some, may never feel like it will arrive, and for others they may reach it very quickly. The important thing for us to note is that everyone's experience is truly unique and should be valued as such.

Illness places people on a different timeline to what can be considered "normative time". Normative time is a linear form of time dictated by societal expectations, in which we travel through or reach certain life stages at given ages. For those who are unwell, or trying to heal, these life stages change, or must be delayed. This can create feelings of pressure or disappointment and, without proper understanding, a feeling like you are struggling to keep up. Healing is not linear and is individual to everyone.

Mapping Surgery on the Body

The artworks displayed in this section demonstrate that the felt experience of the body does not always correspond to the way the body looks. These are bodies which have undergone a profound transformation, whether or not that change is immediately visible on the surface of the skin or in the shape of the body. As you will notice from these works, the post-surgery body is a landscape of changed sensation, numbness and many other traces left by treatment and illness.

Notes from Elizabeth

Elizabeth wrote these as her contribution to the project, her words provide an alternative route to access lived experience, and the artworks in the space.

The Image in the Mind of the Patient

We all have a mental image of ourself. How does that receive and absorb the intervention of cancer and mastectomy? Does the internal self-image change? Do we retain the original image; does a new one take over; is it some kind of hybrid? Do we consciously create a new version, and if so when and how?

The Image that the Patient Sees of Herself in Real Life

Every post-surgery patient has to confront herself in the mirror for a first time. By then we have made decisions - reconstruction of different kinds, or a fundamentally changed body with a scar or scars. These decisions are made for a wide range of deeply personal and mainly psychological reasons.

The Image that is Seen by Lovers and Partners

This is complicated. Our bodies have sustained massive change. We are fundamentally different. We may feel a loss of confidence. The situation is new and unknown. In what ways does this new body enter into an existing relationship? How does it affect the partner? Does s/he need help and support in accepting the change in the body and the person? What happens over time?

The Image that May or May Not be Available to the Rest of the World

Post-surgery most of us choose to retain our existing clothing; both reconstruction and prostheses enable clothing to hang correctly.

Athletes have done much in bringing prosthetic limbs into view, and we see people doing amazing things to change the perception of aids such as canes and wheelchair use. But the breast is most usually a private area and the rest of the world is largely unaware of the changed body.

Within an all-female environment such as gym changing room it is possible to be naked without inviting any comment or discomfort - but would settings such as an existing nude swimming beach be secure and comfortable? Post-surgery tattooing is an interesting and creative response that brings the patient strongly back into a current body presentation. Some game-changing women have designed and made post surgery clothing that responds to the new body and reveals and celebrates it. There is a great opportunity for underwear design to embrace this sector and provide positive innovative designs that work well for post-mastectomy patients, and offer new design approaches.

Let us reposition the post-surgery body as an achievement, something to be genuinely celebrated. We don't need to hide or feel embarrassed. There is a real lack of positive images of breast cancer. The work created by the 'Empowered Journeys' participants makes a vigorous, honest and valuable contribution.

Acknowledgements

With thanks to Victoria's Secret for funding this project, without their help it would not have been possible.

Many thanks to the Future Dreams team for their unwavering support and dedication, and for volunteering their space and their time to the project.

Many thanks to the University of Glasgow for supporting this PhD project, more specifically Dr Alexandra Ross and Dr Dominic Paterson who are the supervisors on this project.

With thanks to the amazing workshop facilitators, Alice Haskell and Eloise Birtwhistle, who led us through some wonderful workshops.

It would be remiss not to acknowledge the support of the Binks Hub and the University of Edinburgh Library, who have facilitated many moments of collaboration and knowledge exchange over the course of the project.

Finally, a huge thank you to the amazing co-curators who dedicated so much of their time, energy and resources to this project. Witnessing the community that we have built over the past year has been truly incredible.



Need Support?

Despite the intentions behind this exhibition, it may have left you feeling overwhelmed. There are support networks in place to help you, so please do not hesitate to reach out:

Future Dreams

020 4558 2950 info@futuredreams.org.uk https://futuredreams.org.uk/

Maggie's

0300 123 1801 enquiries@maggies.org https://www.maggies.org

Moobs

https://www.moobs.uk/

Macmillan

0808 808 00 00 https://www.macmillan.org.uk/

BRCA+ Chat

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Samaritans

116 123 https://www.samaritans.org/



