



Sex, Cancer and Art Textile Activism: Empowering Patients and Challenging Health Professionals

Colette Dobson

Project Details

Name: Colette Dobson

Title of Output: Sex, Cancer and Art Textile
Activism: Empowering Patients and Challenging
Health Professionals.

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Output Type: Other

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Cover image, *I don't function anymore* (2017)

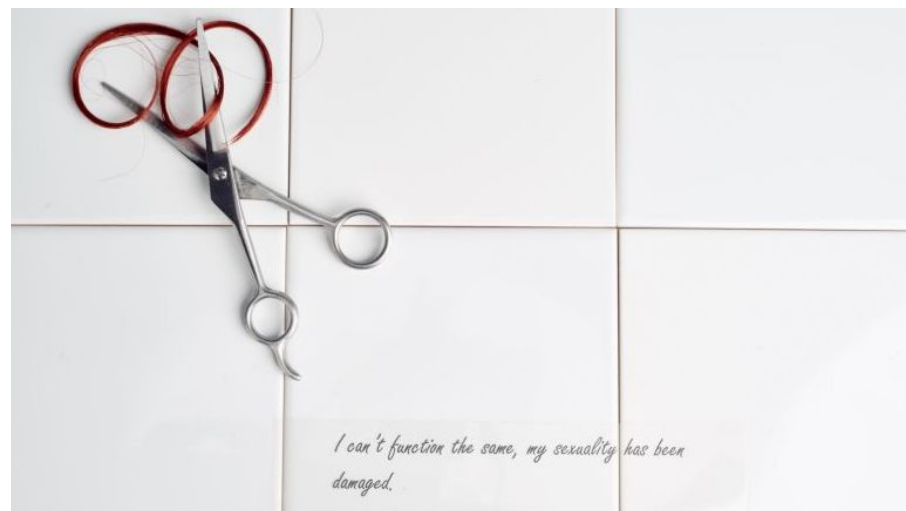


Fig. 1. *I don't function anymore* (2017)

Colette Dobson



Fig. 2. *Sex is painful* (2017)

Elizabeth Couzins Scott and
Colette Dobson



Fig. 3. *Loss* (2017)

Amanda Clayton

Introduction

Description

Sex, Cancer and Art Textile Activism: Empowering Patients and Challenging Health Professionals is a multi-faceted textiles and healthcare research project which originated in 2013. It explores how cancer sufferers can use textile arts practice to communicate with healthcare practitioners.

Dissemination

Dobson has presented the research at 3 international conferences, a range of educational workshops, MacMillan Cancer Support and Information Study Days, and through a toolkit for NHS patient consultations, 1 published paper, 2 symposium papers, and a patient/artist coproduced website with downloadable content.

Conference presentations include: **(1)** The 3rd Cheshire and Wirral Partnership NHS Foundation Trust International Conference on Living with Cancer and Sexuality (Prostate Cancer) (Manchester, 28/01/2014); **(2)** The 4th Cheshire and Wirral Partnership NHS Foundation Trust International Conference on Living with Cancer and Sexuality (Breast Cancer) (Manchester, 10/02/2018); and **(3)** The 14th Congress of the European Federation of Sexology: From Sexology to Sexologies (Faro Portugal, 9-11/5/2018) (300 attendees).

Workshops have focused on communications skills with medical students and practitioners. They include sessions at Kings College London (4/6/2015) (300 midwifery and obstetrics undergraduate attendees), the Cheshire and Wirral Partnership NHS Foundation Trust Research Conference (Wirral, 25/9/2018) (200 delegates), and the UCA Damage and Repair Symposium (2/3/2017) (105 delegates).

Results from participant emotional engagement evaluations have been published in the *Journal of Sexual and Relationship Therapy* (Routledge, 2016).

The research has produced practitioner resources that are now used by the Christie NHS Foundation Trust's Gynae-oncology Department, and by Macmillan Services for professional training sessions.

Introduction

Statement

Led by artist Colette Dobson, 'Empowering Patients' uses ComMA (Communication Medicine and Art) principles to investigate means of helping patients articulate their experience of relationship or sexual problems and other difficult emotions by cancer and its treatment. The research examines how non-verbal, textiles communication boosts patient confidence; it especially focuses on how this communication generates equality between patient and practitioner as both attempt to understand what the communication and the situation can mean for them.

Dobson conducted the research in hospital environments, working collaboratively with Dr Josie Butcher (Psychosexual Consultant, Cheshire and Wirral Partnership NHS Foundation Trust) (CWP). Artist-led workshops introduced female cancer patients to textile arts. They encouraged these patients to use the textile practice as a means of communicating any issues they struggled to discuss in spoken conversation with healthcare professionals. Patient responses were monitored, and the methodology underwent continual refinement to identify optimal ways of using non-verbal communication in medical settings.

Testimonials and evaluations have proved that the work has changed clinical practice and improved the outcomes for the patients' sexual wellbeing. The patient focus group members were empowered because the research gave them a way to communicate to healthcare professionals with less risk of embarrassment or anxiety. They were also empowered because they became able to support other patients, cascading the communication practices throughout new groups of patients and practitioners.



Fig 4. Separation (2015)
Colette Dobson

Aims and Objectives

Evidence shows that cancer patients often experience sexual and relationship difficulties during and after their diagnosis and treatment. Patients and health professionals can find it difficult to discuss these issues, which can lead to poor diagnosis and treatment. This research aimed to improve communication opportunities between cancer patients and health professionals by developing a range of arts-textile-based communications tools.

To achieve this aim, the research's objective was to find a methodology for using non-verbal communication that would then allow patients to express customarily private details and worries about their bodies and sexuality. Doing so, the research would provide new communication options to patients and practitioners, and it would provide patients an artistic and possibly collaborative outlet for their concerns.

Research Questions

Could textile art provide a non-verbal 'bridge' between patients and health professionals, enabling them to attend to issues that patients may feel uncomfortable discussing in clinical settings?

Can collaborative work with artists help patients to express their sexual health problems with greater confidence?

Could any emergent arts textiles methodologies be repurposed into tools for use in the clinical environment or as an online presence that would then support patients with medical, emotional, and communication advice?

Research Context

'Empowering Patients' is fundamentally informed by the 'Subversive Stitch' movement in 1980s arts textiles. In *The Subversive Stitch* (London: 1984), Rozsika Parker traced how Western cultures treat embroidery as a domestic, feminine activity. Both this book and the 'Subversive Stitch: Women and Textiles Today' exhibitions (Manchester, 1988, curated by Pennina Barnett and Jennifer Harris) showed how cloth work could be repurposed for political engagement and a subversion of gender conventions.

The research develops these socio-historical principles by using cloth as visual language for shaping and sharing personal ideas. As Lesley Millar wrote introducing this methodology for the 'Cloth and Memory' exhibition and conference (Saltaire, 2013), repurposed textiles can explore 'the expressive potency of cloth as a communicator of human experience' (transitionandinfluence.com/cloth-and-memory).

The ComMA group built on this earlier work in 'Empowering Patients'. As Millar quotes Dobson in *Radical Threads 1962-2012: The 62 Group of Textile Artists Celebrates 50 Years* (Kent: 2011), 'the work has its routes in textile history and practice, the language of cloth and stitch being the pivot around which social history is expressed'.

As part of 'Empowering Patients', Dobson created a physical cloth 'dictionary' to underline the language concept. It is titled *The Visual Language of Construction and Reconstruction*. This artefact helped to show patients that they could communicate with cloth and with textiles processes, and it introduced the principle that they could repurpose and manipulate cloth and textiles processes for their personal expression.



Fig. 5. *Insertions* (2016)
Colette Dobson

'Empowering Patients' contributes to new modes of medical art textile activism. It expands clothing-based work, as represented by Rhian Solomon's socially engaged work, which uses 'clothing-based approaches' to document women's experiences of cosmetic surgery, weight loss, and reconstructive surgical interventions as breast cancer treatments (rhiansolomon.co.uk/about).



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Research Context

The uncomfortable realities of surgery provided further context to the research's development of a textiles-based language. Textiles could emulate surgical procedures, marks, and scars through their insertions and folds.

In the solo exhibition 'Emerging Reality: The Rouge Butterfly' (R Space, Lisburn: 2017) artist and cancer survivor Heather Burgess referenced how stitch's tools and processes can visualise 'the precarious nature of the cancer treatment journey'. Dobson opened this exhibition by presenting ComMa's approach to visualising a patient's pain and distress. For both Dobson and Burgess, recreating surgeries using textile methods could help patients to see that they could use different materials and processes to express difficult, intimate issues.

However, the research aims required that the work avoid aiming for closely representational work. The patients and artists created works to present to health professionals as challenges. These works' non-representational components would seem unfamiliar to health professionals, then leading them to an awareness of how the patient can find the oncological 'world' alien and difficult to understand.

This balance of representational and non-representational work is informed by arts textiles research into the balance between 'change' and either 'damage' or 'repair'. In the exhibition 'What do I need to do to make it OK' (2015-2016), curated by Liz Cooper with a supporting symposium, 'On Damage and Repair' (UCA, 2016), textiles practitioners investigated ways to say when 'change' becomes 'damage' and whether 'repair' is restorative or if it just stabilises something that is permanently changed. Dobson's symposium paper focused on how art textile practice motivated cancer patients to consider this question of 'repair' about psychological damage.

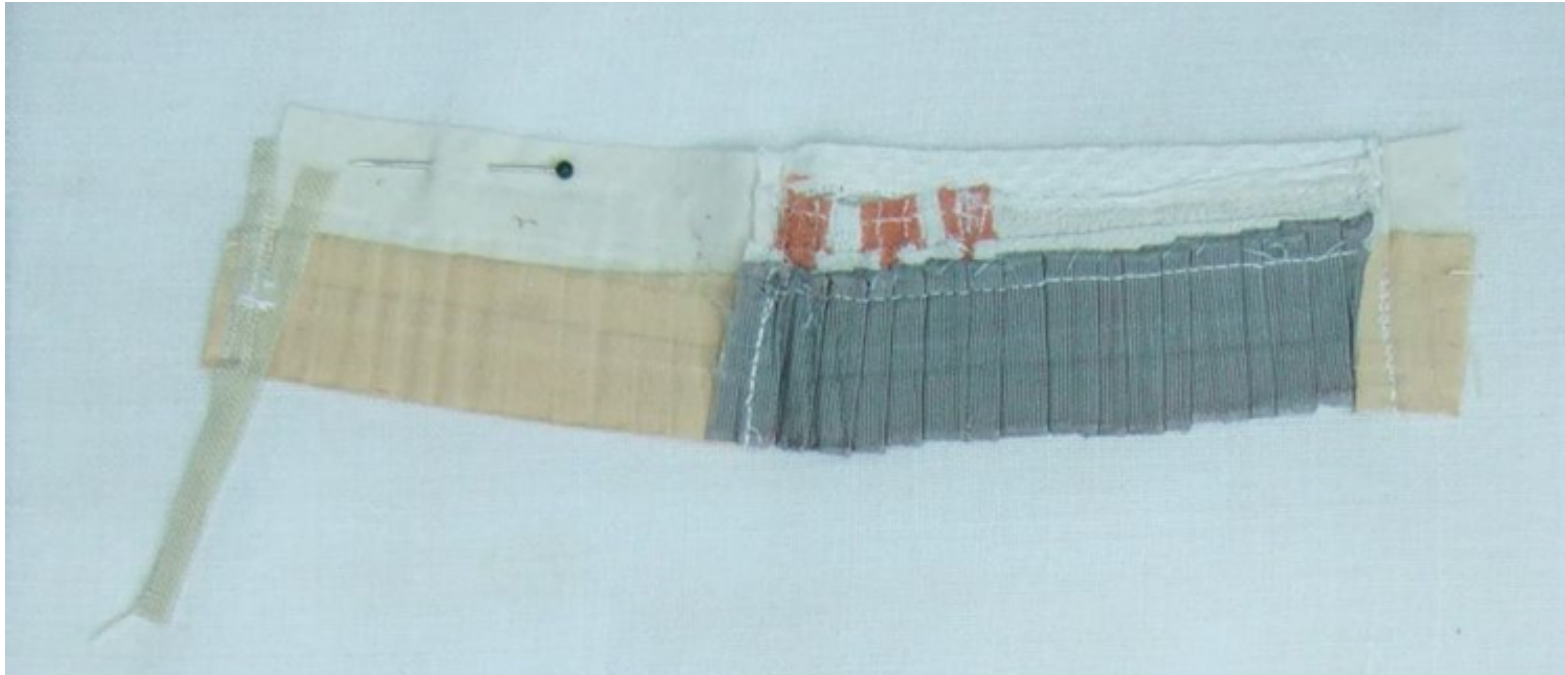


Fig. 7. *Folds – reducing and reshaping* (2016)

Colette Dobson

As well as theoretical approaches within the arts, 'Empowering Patients' is shaped by the NHS Patient and Public Participation Policy (2017) ([england.nhs.uk/wp-content/uploads/2017/04/ppp-policy.pdf](https://www.england.nhs.uk/wp-content/uploads/2017/04/ppp-policy.pdf)). This Policy underlines the Service's need to explore innovative ways to reach out to communities, to avoid assumptions, and to address health inequalities through social partnership. By working with ComMA, the NHS built upon its existing training provision. The research explored and documented new methodologies and skills for inclusive communication between practitioners and patients. It formed part of the CWP's 'Zero Harm' Campaign (2014) and was selected for inclusion in the CWP's *Big Book of Best Practice, 2016-2017* (webstore.cwp.nhs.uk/bbbp/bbbp1617.pdf (p. 37)).

Research Process: Overview

The research began in 2014 as a response to patient evaluations of practitioner-patient communications, which were delivered at the CWP's International Conference on Sexuality and Cancer (prostate cancer) (2014).

In 2016, Dobson and Butcher developed a study protocol to engage with patients in arts textile sessions, winning the necessary NHS supervision and HRA ethical approval to perform the research.

In 2017, collaborations with a focus group of patients produced artworks for dissemination to healthcare professionals as training aids. This dissemination began in 2018, leading to healthcare professionals conducting further evaluations of the artworks as potential aids to future patients.

CWP continues to use artworks from the research as part of internal training, clinical consultations, and developing new practice guidelines.



Fig. 8. *Ask Before you Mark* (2017)
Elizabeth Couzins Scott

Research Process: Part 1

Artist's Introductory Workshops for Patients 01/2017 - 06/2017

At this initial workshop, Dobson introduced breast cancer patients to the language of textiles by using *The Visual Language of Construction and Reconstruction*.

This textiles dictionary outlines the terms and characteristics of textiles art practice and relates them to a healthcare context. It presents cloth preparation, marking out, shaping, removal of area, seaming, pleating, padding, and invites personal comparisons to surgical procedures and bodily developments.

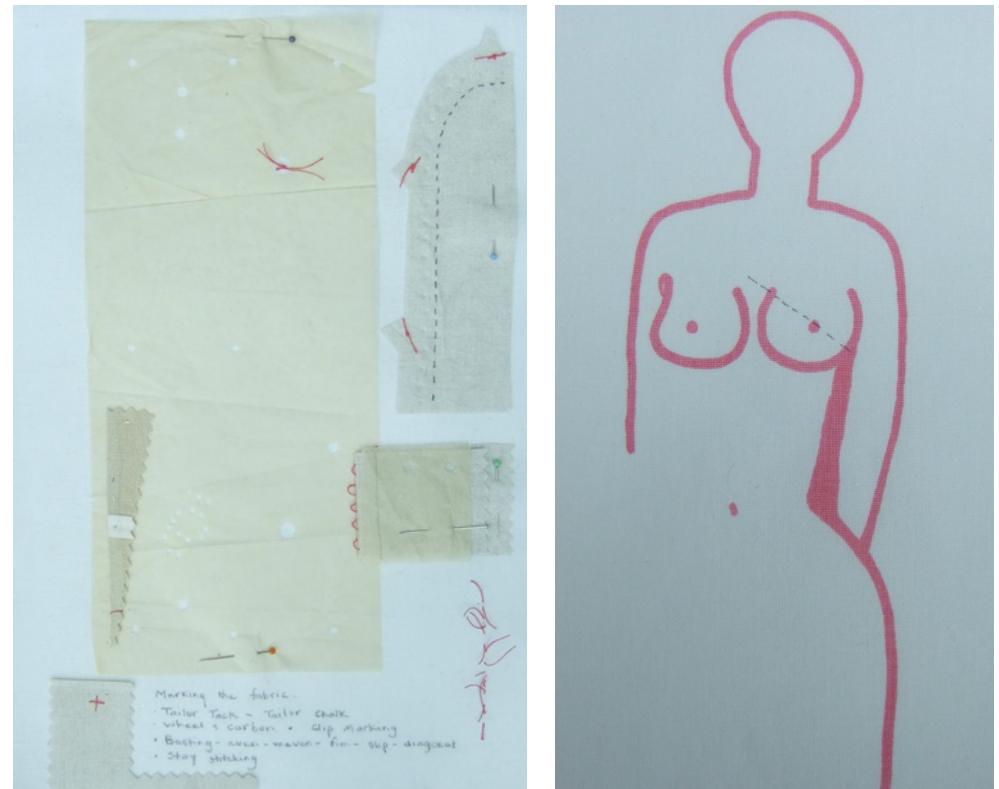


Fig. 9. *Dictionary of Construction and Reconstruction* (2016)
Colette Dobson

Research Process: Part 1

Removal of excess.

Darting.

Gathering.

Pin tuck.

Pleat.

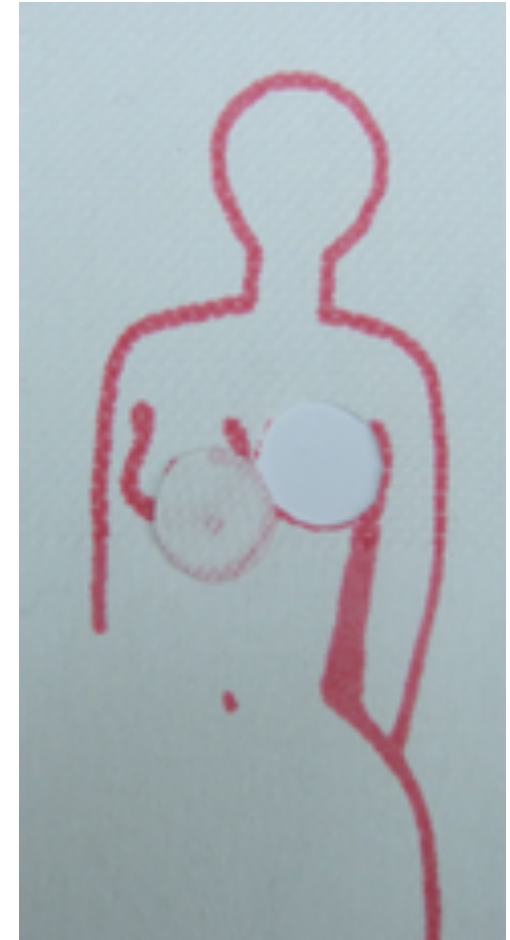


Fig. 10. *Dictionary of Construction and Deconstruction* (2016)
Colette Dobson

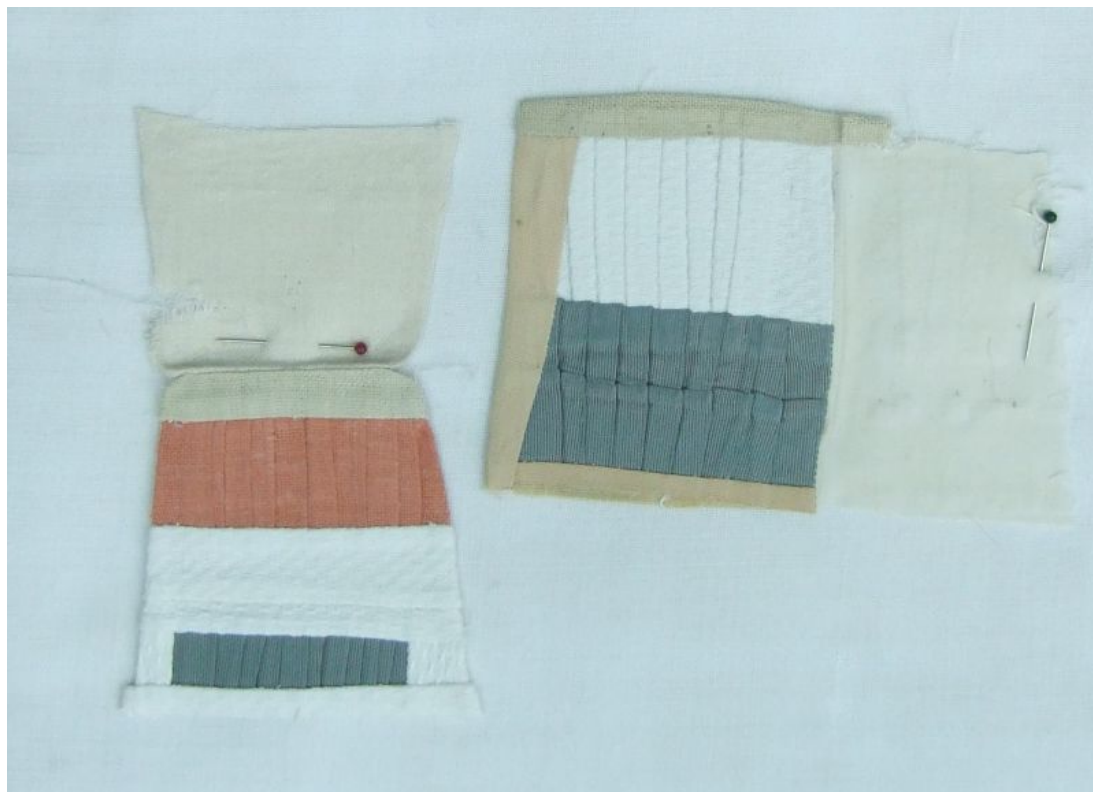


Fig. 11. *Folds* (2016)
Colette Dobson

Patients were encouraged to create non-representational works. Instead of trying to depict themselves as particular objects, they were encouraged to create representations of their worries and of any issues that they struggled to talk about. They could present healthcare professionals with their concerns, making their difficulty in talking become a new frontier to explore in their treatment.

Research Process: Part 2

Patients' Responses to Workshops. 06/2017

A range of objects made by Dobson symbolically referenced the concept of an individual cancer journey. Patients were encouraged to alter items that they associated with fear, including surgical gowns. Patients drew on, collaged, and wrote on these objects, allowing the researchers to see how patients expressed their emotional responses.



Fig. 12. Patient's response (2017)

Before surgery, feminine.

Fig. 13. Patients response (2017)

After surgery, the vagina became a no entry sign surrounded by barbed wire and accompanied by an image of the patient's mastectomy.

Patients' Responses to Workshops



Fig. 14. Patient's response (2017)
The workshops were created as safe, supportive spaces where patients could express themselves without having to worry about fitting criteria or meeting judgment.

Research Process: Part 3

Patients' Collaboration with Artists 07/2017-12/2017

The collaboration with the patients allowed them to discuss Dobson's and three fellow artists' works in progress that had responded to the patients' initial works. These discussions created a supportive environment for self-expression and discussion.

Evaluating the patients' responses enabled the artists to develop responses to the patients' difficult psychological issues. These included including self-image, fear, anxieties, and physical changes including damage to vaginas and a struggle or inability to see themselves as sexual beings. These response works showed patients how art textiles could enable dialogue about their conditions and concerns.

The artists work ranged from visualisations of damaged vaginas, depictions of loss of hair and sexuality, and portrayals of fragility and fear, and used a combination of textiles and hospital-environment materials, including hooks, blades, hair, soap, organza, and lace.



Fig. 15. Patient's responding to artists ideas (2017)

Fig. 16. Artist's response (2017)

Research Process: Part 3

Patients' Collaboration with Artists

Patients responded by speaking intimately and about intimacy:

'I found my hairdressers hugely supportive, I could talk to her when I could not talk to my doctor she was very upfront'.

'I don't function sexually the same anymore'.



Fig. 17. Patient talking through their response to Colette Dobson's work (2017)

Patients' Collaboration with Artists



Figs. 18 & 19. Patients working with their text on garments (2017)

Patients had identified words relating to their emotions, bodies and sexual function. They identified the nightdress – a significant garment loaded with socio-cultural meanings – as among the clothing that they would use as a canvas to express themselves. They incorporated verbal and non-verbal communication into the same work, placing text on garments to be stitched or printed.

Research Process: Part 4

Artist's Responses to Patients' Communication Difficulties

Patients talked of difficulty discussing their sexual problems with their health professionals and partners. By contrast, many of them identified their hairdresser as someone they could confide in.

Dobson chose the hairdresser situation as a line of research. Loss of hair was an outward sign of the treatment for cancer and acceptable to talk about, but the loss of their sexual identity due to the treatment was a very difficult issue to discuss. As patients repeated versions of the phrase 'I don't function sexually anymore', Dobson used objects that were once used to beautify their hair. Hairbrushes and hairdressing scissors were reconfigured to no longer function, through by weaving, plaiting, sewing, and knotting hair. The patients added their ideas to this arts practice, leading to the use of plugholes and soaps to express their thoughts about the significance of cleansing and hair loss.

Links attached to the following works relate to the events through which creative outputs have evolved.

Figs. 20 & 21. *I don't function the same anymore*, (2017)

Colette Dobson <http://eprints.staffs.ac.uk/id/eprint/5196>

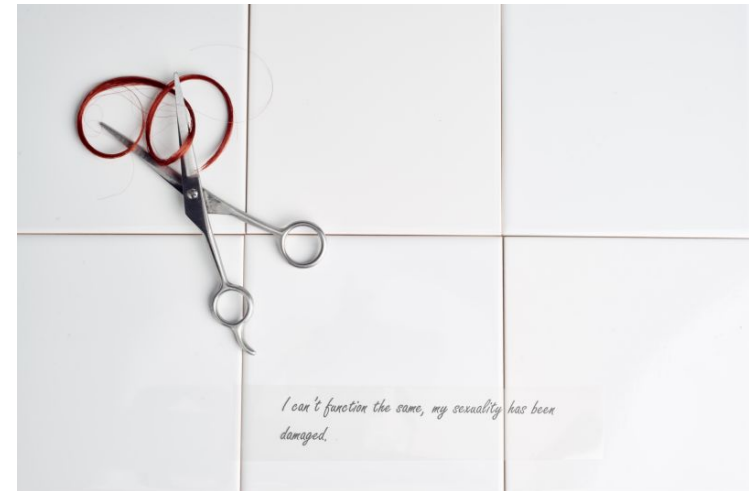




Fig. 22. *Sadly it not only your hair that goes down the plughole your sex life can do too* (2017)
Colette Dobson <http://eprints.staffs.ac.uk/id/eprint/5196>



Fig. 23. *Mourning* (2019)
Colette Dobson www.commedart.com



Fig. 24. *I don't function anymore* (2017)
Colette Dobson <http://eprints.staffs.ac.uk/id/eprint/5196>

Documentation of Outputs



Fig. 25. *Loss* (2017)
Elizabeth Couzins Scott <http://eprints.staffs.ac.uk/id/eprint/5196>

Fig. 26. *No one told me ...* (2017)
Elizabeth Couzins Scott and Colette Dobson, (Now used by the Christie NHS Trust Gynae-oncology Department) <http://eprints.staffs.ac.uk/id/eprint/5196>



Research Insights

Artworks as Educational Tools in Clinical Practice

The research developed an innovative collaborative methodology where patients work with artists to learn new ways of expressing their personal emotions and anxieties. Arts practice then increases patient confidence and patient ability to communicate with health care professionals.

Collaborative workshops have confronted healthcare practitioners with disorienting communications, which gives the practitioner a sense of the patient's perspective when confronted by a strange, upsetting medical world. These workshops have proved their validity as new pathways of learning for health professionals.

Evidence shows that the artworks can be used in clinical practice to support patients in understanding their changed sexual anatomy and have improved patients' clinical outcomes. New training strategies have embedded the artwork as learning tools to improve health professionals' knowledge of post-cancer patients' sexual problems.

The vaginas ['Nobody told me', artwork by Couzins Scott and Dobson] colloquially known as 'the doughnuts' help patients to understand why using particular products (e.g., vaginal moisturisers or a lubricant) or using the dilator may be helpful, which I have found makes them more likely to comply with the guidance and move forwards after treatment. It can be much more difficult for them to fully grasp the concepts if we are just explaining, whereas if they have aids to actually see and feel then they (and in some cases their partners too) gain a better understanding. This helps them work together better as a couple and leads to improved relationships. I would estimate that around 25 of our patients per year benefit from the use of the doughnuts in consultations. As a result, the vast majority of these patients were discharged from the clinic with better outcomes, with just a small number being referred on for further support. I show the products to new members of staff who join us which helps their understanding of how the treatment can affect patients. Gynae-oncology Specialist Clinical Nurse for the Clinical Advisory Team, the Christie NHS Trust

Research Insights

Artworks as Educational Tools in Clinical Practice

Between 2016 and 2017, the research was used in 20 Study Days for Macmillan Cancer Support and Information Service. Each study day worked with up to 30 delegates and used ComMA's artwork to develop the educational experience. The work has shown how combined artist-patient methodologies can produce training tools for practitioners and for their support services, including consultant psychiatrists within cancer-services centres.

Seeing people's experiences communicated through the artwork is powerful, and sometimes shocking, therefore adding a new, deeper perspective to even the most familiar of issues. This has taken my understanding to a new level and deepened my connection with the patient experience, especially in terms of the sense of loss. As a result, I have greater levels of empathy when I am listening to patients communicating the impact of their sadness and loss, whether that is loss of a breast, hair, sexual function, or femininity... When seeing patients who have issues resonating with the key research themes, I have discussed the research and sometimes signposted them to Me Again and suggested that they engage with the artwork. This has the benefit of validating their feelings and connecting them with additional sources of support.

Consultant-Liaison Psychiatrist, Clatterbridge Cancer Centre.



Fig. 27. Loss (2017)
Amanda Clayton

Research Insights

Patient Advocacy

'Empowering Patients' has shown that artist-patient communication methodologies have a cascade effect. Patients become able to speak to other, newer patients about hospitalisation and about how to proceed through the 'journey'. This methodology gives patients agency to help others, which can give them empowerment after having gone through the ordeal of suffering from cancer. The patient group has seen members become patient advocates using the work of ComMA at Macmillian events and with their support groups. One patient applies insights from the research in her role as Director of a related Community Interest Company (a monthly support group for women with a cancer diagnosis), which now provides online support due to the Covid-19 pandemic. Another from the patient group has set up a local support group (2020). As one patient, Kay, told an audience of 200 at a Breast Cancer Research event (26.02.20), the research has empowered her to advocate for cancer sufferers and apply its participation strategies to help others:

The whole process of being involved in the research has given me the opportunity to express how I felt throughout 'my journey'. I've produced artwork myself that I didn't know I was capable of doing and have always been encouraged by the wonderful artists. I now feel empowered and want to help other women by getting information out there in as many places as possible.

Dissemination: Overview

Dobson, Colette, Macmillan Cancer Support. Patient advocacy talk and pop up exhibition. Cheshire. 26/02/2020.

Dobson, Colette, Me Again. Presentation: 'ComMA Work with Cancer Patients'. Brimstage, Wirral. 4/10/2019.

Dobson, Colette, Butcher, Josie, Atkinson, Angela, Couzins Scott, Liz and Clayton, Amanda (2018)
Cancer and Sexuality sex and relationships - empowering Patients and Health Professionals through Art. In: 14th international of the European Federation : From Sexology to Sexologies, 11-13 May 2018, Faro Portugal.
<http://eprints.staffs.ac.uk/id/eprint/5199>

Dobson, Colette, Butcher, Josie, Atkinson, Angela, Couzins Scott, Liz and Clayton, Amanda (2018)
Cheshire Wirral Partnership - Research Conference. In: CWP Research, 25 September 2018, Thoroton Hall Wirral.
<http://eprints.staffs.ac.uk/id/eprint/5195>

Dobson, Colette, Butcher, Josie, Atkinson, Angela, Couzins Scott, Liz and Clayton, Amanda (2018)
Breast Cancer Communication, Sex and Relationships Opening Conversations-Patients day. In: CWP NHS Trust Breast Cancer Communication, Sex and Relationships - Opening Conversations Patients Day, 2 -2 April 2018, Sycamore House CWP.

Dobson, Colette, Butcher, Josie, Clayton, Amanda, Atkinson, Angela and Scott Couzins, Elizabeth (2017)
4th International Conference - Sexuality and Cancer Breast Cancer. In: Sexuality and Breast Cancer, 10 November 2017, Manchester Conference Centre. (Unpublished).
<http://eprints.staffs.ac.uk/id/eprint/5196>

Opening of Exhibition: 'Emerging Reality: The Rouge Butterfly'. Art Space ('R Space'). Lisburn 7/01/2017.

Dissemination: Overview

Dobson, Colette, (2016)

Repairing Emotional and Sexual Damage caused by Cancer- International Symposium UCA-University for the Creative Arts. In: Damage and Repair - How Can I Make it Better, February 2016, University of the Creative Arts.

<http://eprints.staffs.ac.uk/id/eprint/5201>

Dobson, Colette, and **Clayton, Amanda** (2015)

Transition - Challenging Communication Skills through Textile Art. In: Transition, 4 -4 June 2015, Kings College London - Department of Midwifery and Obstetrics.

<http://eprints.staffs.ac.uk/id/eprint/5192>

Dobson, Colette, Butcher, Josie, Atkinson, Angela, Couzins Scott, Liz and **Clayton, Amanda** (2014)

3rd International Conference Living with Sexuality and Cancer -Prostate Cancer. In: 3rd International Conference Living with Sexuality and Cancer, 28 January 2014, Manchester Conference Centre.

<http://eprints.staffs.ac.uk/id/eprint/5202>

Dobson, Colette, and **Butcher, Josie** (2016)

Cancer and Sexuality : Opening Difficult Therapeutic Conversations and Challenging Assumptions using the Language of Art Textiles. Sexual and Relationship Therapy International Perspectives on Theory, Research and Practice.

<http://eprints.staffs.ac.uk/id/eprint/2103>

Website: commedart.com

Dissemination

Conference and Experiential Workshop 10/02/2018

The work was presented by the artists and patients at international conferences as experience-based workshops. All events were evaluated, and the evaluations used to develop the tools for the research outcomes.



Figs. 28 & 29. Experiential workshops (2017)

'This workshop speaks so much more than any amount of PowerPoint presentations. These images touch the soul, speak more than words, more deeply than "cognitive" understanding... I need to talk to my patients more'. Health Professional, breast cancer conference

Dissemination

Conferences, Patient Events, Health Professional Study Days, Tools for Patients
04/2018 - 2021

The work was disseminated as training for health professionals through both the NHS and the Macmillan Cancer Support Information Services. A patient day conference introduced cancer patients to the work as a means of supporting and encouraging communication around their personal experiences. Dobson presented the work to this conference with focus group patients, who acted as advocates to a patient support group. Dobson collaborated with a patient to produce artwork for a pop-up exhibition at a Macmillan charity event (26/02/2020).

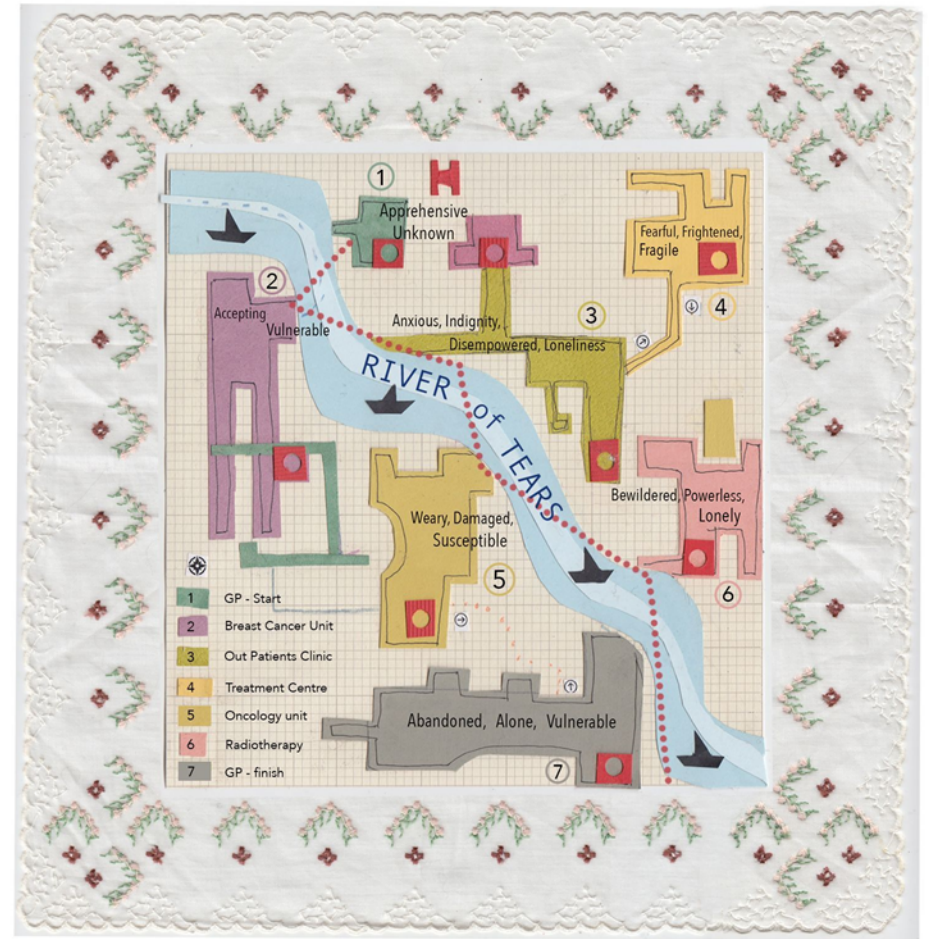


Fig. 30. *River of Tears* (2020)

Colette Dobson, made in collaboration with a breast cancer patient for Macmillan cancer event.

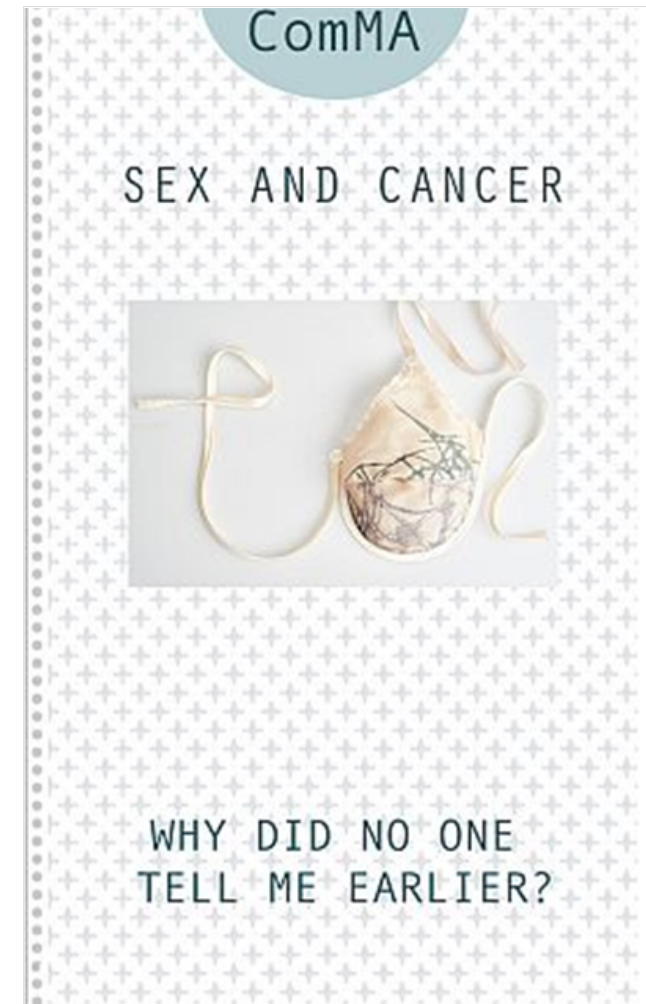
Dissemination

Website, 02/2019-12/2020

Dobson worked with the patient focus group to disseminate the research to the public. They aimed to reach a wide audience, and they focused on early intervention and support to help new patients communicate more confidently with health professionals, their partners, and their families.

Together, Dobson and the patient group produced a website that empowered the patients to offer information to other patients, and that presents advice on how practitioners might better communicate with new patients and their families. The website hosts a downloadable notebook that patients can read and use in preparation for a medical visit. Dobson designed this notebook in response to insights gained from the research. As the focus group indicated, patients found that they wanted something tangible but expressive, an object that they could personalise when they underwent treatment: www.commedart.com

Fig. 31. *My little notebook* (2020)
Colette Dobson and patients



Dissemination

Website




Figs. 32 & 33. *My little notebook* (2020)
Colette Dobson and patients

The notebook offers information from the patient's perspective. It guides them with what to ask, how to ask it, and what to do with the Answers.

Dissemination

Website


Information for your partner



Ask your partner to come with you to talk about possible effects to our relationship from my treatment.


If you go early to talk to the Doctor or your health professional, you could get information and help you talk about future problems you may have in your sexual relationship.

Action before problems arise is better, there is less anxiety and can help before painful sex may have occurred.



Many women experience **hormonal changes** following chemotherapy, surgery and medical treatments for Breast Cancer such as:

Vagina soreness, dryness, itching, painful sexual intercourse.

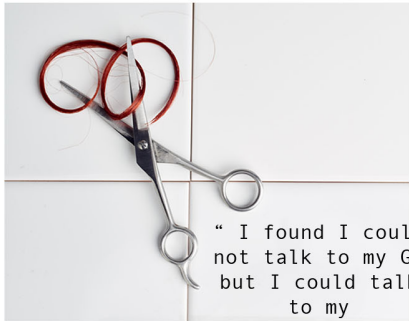


It's vitally important to get expert **advice** before you try any treatments. Please ask your Health professional for information on vulva and **vaginal care**.

I am needing help to find a way to make my partner **listen**. Is there anyone you could suggest I talk to?

I need help with **marriage problems** because the sexual problems are causing issues, is there any help available?

How can I make other people understand me? Is there anywhere I can talk to people who have **similar experiences** to me?



“ I found I could not talk to my GP but I could talk to my hairdresser, she was **upfront** and **supportive**.”

Fig. 34. Pages from *My Little Notebook* (2020)
Colette Dobson and patients