The Patient is Performing

As

Unexpected

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In collaboration with Transplant Selves

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Abstract

This practice led research asks how both the experience of serious illness and the medical institution affect the long-term hospital patient, and in what way an art practice can help redefine the post-hospital, post-transplant artist.

The project draws on my work as an art psychotherapist in an adult mental health secure unit, as well as my own experience of being a patient in hospital isolation for the treatment of Leukaemia. I am interested, from the perspective of an artist, in how identity and ideas of self are disrupted by illness and medical intervention. My main focus is on the phenomenon of allogeneic transplantation, the procedure that I underwent as part of my treatment. This involves transplanting genetically different cellular material, from the same species, from a healthy donor to the recipient patient. The result of this, in medical terms, is called a Chimera (also the name for the Greek, three-headed mythical creature).

In my studio practice I explore the concept of the Chimera through the relationship of similar but different methods and materials: still and moving image and print, film, performance and fictional writing. As part of this experimentation I have developed what I have termed ‘Transplant Selves’: selves that are formed from an imagined reconfiguration of my new donor cells and DNA. These hybrid selves are contextualised in relation to psychoanalysis as well as poststructuralist ideas of multiplicities and performativity. I reference post-feminist and posthumanist texts, and fictional novels, including science fiction and populist writing. I draw on queer theory, self-storytelling and health activism.

The research project outlines major shifts in both my academic thinking and my art practice. In questioning the limiting concepts of patient identity prescribed by the contemporary medical institution, I offer visual and textual ideas on how the artist-patient might perform differently, and in unexpected ways.
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Signature:

Date: 5th September 2018
1. Introduction

*The Patient is Performing as Unexpected* is a practice led research project that began with my diagnosis of Acute Myeloid Leukaemia in 2003. The treatment for this kind of cancer temporarily destroyed my immune system and meant that I had to spend long periods of time in protective hospital isolation rooms, typically for five to six weeks at a time. Over a number of years I spent a total of ten months in this kind of isolated environment. Alongside this I was an inpatient on many other kinds of wards for secondary conditions caused by the treatment.

From early on I began to keep diaries that recorded my experience of being in hospital (see Appendix 2 for excerpts from these diaries). Here is an entry from shortly after I was first diagnosed, an indication of some of the difficulties I was having in being a patient:

31st of August 2004  
(After first hospital admission)

Bullying  
Towing the line  
Infantilisation  
Accepted culture  
Patients as victims  
Nurses as saints  
Doctors as God  
Voice of the patient  
Patient empowerment

These early thoughts provided some of the main questions for this research project: How do the existing power differences of the medical institution affect the agency of the hospital patient? How can this be transformed? How can the patient perform in ways that are different from the expectations of the institution?

At the time, my own response to the sense of disempowerment, both physically and psychologically, was to return to activities as an artist. I took up knitting (the perfect occupation for long periods in isolation) and drawing in sketchbooks (figs. 1 & 5).
Fig. 1: Pages from hospital sketchbooks, 2003-06
This led directly to my reengagement with a professional art practice. One of the main inspirations for this was an exhibition held in the corridors of the haematology ward by artist and former patient, Andrea Duncan. Her project and publication of the same name, *Humanscape*, documented patients’ drawings and comments alongside her own collaborative work with the haematology laboratory (Duncan, 2002). During my own time in the hospital isolation room I used the space as a studio and as a gallery, curating and exhibiting work made by friends and relatives.

On leaving hospital I made a decision not to return to my post working as an art therapist on a secure unit in an acute adult psychiatry. Instead, I re-engaged with my printmaking practice, exhibiting and selling my work. I developed *A Room Full of Space*, a research project supported by The Elimination of Leukaemia Fund (fig. 2).

![A Room Full of Space](image)

*Fig. 2: A Room Full of Space, A6 booklet, 2011*

After a relapse of my illness in 2007, and after another extensive period of hospitalisation I went on to establish *The Geography of Wellness*, an art and health project funded by the charity Macmillan Cancer Support. I ran print workshops for others affected by cancer where we adopted Macmillan’s idea of ‘the cancer journey’ as a theme for the workshops. The cancer journey was a metaphor that functioned as an idea to help cancer patients feel
more empowered about their illness: that the experience could be active rather than passive.

The energy and movement of going on a journey seemed a suitable antidote to the stagnation of illness and hospitalisation. This concept influenced my own art practice at the time. I made a literal journey to the Isle of Skye, where I had lived as a teenager, to make drawings and photographs as source material for new work. In my studio I became interested in printmaking as a more explorative method with less focus on the end result, and I experimented with other ways of making prints that involved 3d models, animation and short films (fig. 3). My work as a traditional, commercial printmaker no longer seemed enough to communicate my experience of hospital, illness and near-death. The theme of journeying established the foundations for my practice led research: research as a search. In this way my research began as a quest to find new and different ways of being that might be useful in finding meaning in illness.

As part of my treatment for leukaemia I was given a bone marrow transplant from an anonymous donor. This medical procedure is known as an ‘allogeneic’ transplant which refers to:
... tissues or cells which are genetically dissimilar and hence immunologically incompatible, although from individuals of the same species. (English Oxford Living Dictionaries, 2018)

This kind of transplantation involved the infusion of my diseased cells with those of a healthy donor. The resulting coexistence of the two different cell types in the body is known, in medical terms, as the ‘chimera’, named after the mythical Greek creature with a lion’s head, a goat’s body and a serpent’s tail. These two differing meanings for the chimera, the medical and the mythical, were to inform one of the main themes of my research: the coexistence of two or more contradictory elements, particularly the duality of the medical and the artistic. I have thought of these two differing perspectives in relation to W. G. Sebald’s analysis of the Rembrandt’s painting The Anatomy Lesson (fig. 4), that depicts a dissection of a corpse (Sebald, 2002). Sebald points out the incorrect anatomical representation of the hand of the corpse being dissected by Dr Tulip and his medical assistants. He believes this to be an intentional mistake and suggests that this is to do with Rembrandt’s identification with, and focus on, the victim rather than on the Guild responsible for the medical dissection:

His gaze alone is free of Cartesian rigidity. He alone sees that greenish annihilated body, and he alone sees the shadow in the half-open mouth and over the dead man’s eyes (Sebald, 2002, p. 17).

Fig. 4: The Anatomy Lesson of Dr Nicolaes Tulp, Rembrandt, 1632
The Patient is Performing as Unexpected is therefore a quest, through the lens of an artist, for new and different personal narratives that can resist the more dominant medical voices. In this research project I take inspiration from other underrepresented voices of feminist writers, black poets and queer artists. I also reconnect with my involvement in health activism during the AIDS crisis of 1980’s Britain, with groups such as ACT UP\textsuperscript{1} (AIDS Coalition to Unleash Power).

This studio led research project develops my re-engagement with an art practice that began in my isolation room. It charts my transformation from hospital patient to artist, from traditional printmaker to sculptor, animator, filmmaker, queer performer, writer and storyteller. By drawing on poststructuralist, post human and post feminist ideas of self and identity, I perform as new, expanded parts of myself that I have called ‘Transplant Selves’: a radically different way of performing from the role I was given as a patient on entering the medical institution. My research project is intended as an alternative vision for health professionals that can help transform the patient experience. It is an artist’s manifesto that invites the wounded artist to be free to perform differently- and in unexpected ways.

I have framed my first four chapters in relation to the colours of the traditional method of four-colour printing: Cyan, Magenta, Yellow and Key\textsuperscript{2}. I begin with Magenta, the colour of hospital walls and blood.

\textsuperscript{1} ACT Up was formed in 1987. Around this time I volunteered for AIDS services and, as an artist, made publicity posters and t-shirts. I designed a quilt that became a part of the larger AIDS Memorial Quilt.

\textsuperscript{2} CMYK, Cyan (blue); Magenta (pink); Yellow and Key (black), along with the white of the printing paper, produce most of the other colours in the spectrum.
Fig. 5: Pink Hospital Pyjamas, Image from hospital sketchbook, 2004
2. Magenta

There are two different types of hospital isolation room: those that are designed to isolate the patient and prevent the spread of infectious disease (for example, the Ebola virus outbreak in 2015) and those that are designed to protect the patient who has little or no immune system. It is in the second type of isolation room that I had my treatment for Acute Myeloid Leukaemia. I spent about nine months over a number of years in this kind of space. The purpose-built isolation room is part of a specialised unit within the hospital and functions to protect the patient during chemotherapy-induced neutropenia: a lack of white blood cells that heightens the risk of serious infection. The self-contained space has a positive air filtration system to minimise exposure to harmful organisms, and staff and visitors are expected to wear protective masks, gloves and aprons.

Existing research in relation to the hospital isolation room is mainly from a medical perspective with concerns about the technical efficiency of the room (Schimpff et al., 1975) or about the need for infection control (Preston et al., 1981). There have been several examples of artist’s projects working in relation to this environment. In 2002 Dorset County Hospital devised a pilot research project where live views of local beauty spots were streamed to monitors in hospital rooms with the idea of examining the effects this had on leukaemia patients in isolation. A similar project, Open Window, was presented at a conference I attended at the V & A (Art, Design and New Technology for Health, The Sackler Conference, 2015). Patients in isolation rooms at St James’ Hospital, Dublin, were able to guide robots remotely from their beds through an exhibition at the city’s science museum.

The wider space of the hospital can be thought of in terms of Augé’s (1995) definition of ‘anthropological space’ or the place ‘where strict rules of residence are imposed on everyone’ (p. v111). Yet, paradoxically, the patient in isolation needs to create a sense of the familiar and the illusion of a personal territory - a space that also belongs to the institution. Vidler references Jeremy Bentham’s ‘transparent space’ of modernist architecture that illuminates ‘the rational grids and hermetic
enclosures of institutions’ and Foucault’s observation of this as a fear of ‘darkened spaces’ (Vidler, 1999, p. 169). He describes an exteriorisation of the body- ‘its cell structure has become the object of spatial modelling that maps its own sites’ (p. 167). The institution of the hospital has no hidden corners for dark dreams and imaginings especially, perhaps, in the extra-sanitised space of the isolation room. The hospital space can seem like the antithesis of home, associated with sickness, pain, isolation, loneliness, fear and death. The space needs to be temporarily surrendered to and the body given over to medicine. The patient’s body becomes an object of medical interest where biological and cellular interiors are discussed, a binary splitting of the body and mind, the science and the social. I will discuss this further in the next chapter.

When I was first diagnosed with Leukaemia I had been working as an art psychotherapist in a secure mental health hospital. The form of Leukaemia I was diagnosed with was very acute and needed immediate treatment so my hospitalisation was very quick as was my transformation from health professional to hospital patient. One moment I was part of the system and the next I was in the system. The glitch in my body (the blood cells in my bone marrow were failing to mature) reflected the dis-ease I felt in my new environment and with my changing sense of identity.

When I began working on my research project a similar parallel process happened where I experienced a conflict between different kinds of identities: patient, psychotherapist, researcher and artist. My initial thinking was influenced by my last academic training in art psychotherapy, which in itself was complicated by my interest in different theoretical, and sometimes conflicting, models: Object relations theory, phenomenology, anti-psychiatry\(^3\) and Buddhist philosophy. When I had worked as an Art Psychotherapist on a psychiatric ward, the patient’s movements and relationship with the space were as important as the content of their artwork. Here, the work of child psychoanalyst D.W. Winnicott was useful, particularly his

\(^3\) The anti-psychiatry movement saw traditional psychiatric treatment as more damaging than beneficial and proposed a more social and less biological approach to mental ill health.
concept of Transitional Space that was part of his broader theory of child
development (Winnicott, 1971). This space suggests an intermediate area between
a child’s inner reality and the external environment (mother/parent, family, society).
According to Winnicott this is the place of play and symbolism where the child
learns to differentiate between what is ‘me’ and what is ‘not me’. Although these
ideas were initially useful in linking my identities as therapist and artist, and one
kind of thinking with another, they seem in retrospect to be too limited to psychic
objects and emotional development.

It took some time to frame my work conceptually within an embodied way of
making, rather than within psychological ideas alone. I had to let go of a
professional identity that was practice-led and based in a studio/workshop
environment- albeit a practice that helped others, usually non- artists, facilitate
their own creative expression. This was also true for my method of making work in
the studio in that my work tended to be process led and metaphorical. For example,
in a pre-research commission I made a part-animated film titled Journeymen4 that
was based on the Macmillan idea of ‘the cancer journey’5. In the film I constructed
boxes as objects that related to each other so as to form a landscape- the
background to the metaphorical journey.

I began my studio research for this project by filming myself pouring pink screen-
printing ink onto the cardboard models that were left over from this film. I did this
in a small area that I had marked out within my bigger studio space - the size and
dimensions of the hospital bedside table I worked on when I was a patient in
isolation (fig. 6).

4 From the Geography of Wellness, an art and health project (2012-13) I established with other
people affected by cancer, funded by Macmillan Cancer Support.

5 Macmillan Cancer Support is a British charity that supports people affected by cancer with their
non-medical needs.
The ink pouring obliterated the perfectionism of the geometric cardboard models. I had wanted to disturb the memory of a sterile hospital space and the action was reminiscent of an event that I had experienced in my work on a secure psychiatric ward where one of my, extremely manic, patients had spilled fluorescent paint along the corridors and around her room. Although my ink pouring as process was still very much in the art therapy mode it was, in a way, a literal destruction, or deconstruction, of a pre-research piece of work and a representation of a shift in my thinking (fig. 7).

From my experimentation in the studio, a new form emerged. Using my previous technique of building objects, I constructed a life-size figure from card, pink wool
and pink material that took the form of a sculptural, geometric model, an abstracted figure with a soft pink knitted body. This was designed to be worn and to move in a limited way (fig. 8). My supervisor introduced me to the geometric costumes from Oscar Schlemmer’s 1921 *Triadic Ballet* as well as the Canadian collective *General Idea* and their invention of Miss General Idea (Bonnet, ND), a fictitious beauty queen that acted as an artistic muse for the group and was of a similar wearable, geometric structure. For the RCA research biennale (2015, figs. 9, 10 & 11), I created an environment for the sculpture: a walled off area of the gallery where the walls were painted pink and carpeted in a similar lurid pink. One of the walls of the space was the window to the gallery and so, as with a hospital room, the space represented a private space that was also very public.⁷

For the exhibition publication I wrote a piece called *The Rose Madder Affect: It Wasn’t Me, It Was My False Self*. This told the story of a fictional patient called Rose Madder⁸ and was in the style of a traditional psychoanalytic case study.⁹ This piece was from the perspective of Rose’s psychotherapist, Rose Sélavy.¹⁰ The following is the transcript from the publication: Rose was admitted to hospital with an acute condition that needed immediate treatment and required a lengthy stay in an isolation unit.

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⁸ This was documented as part of the *Adventures of the Black Square* exhibition, Whitechapel Gallery (Blazwick, E. 2015).

⁷ In his 19th century memoir, *A Journey Round My Room* (2012), Xavier De Maistre takes a philosophical view of his private but public space he is imprisoned in. De Maistre created a system for surviving the ordeal through contemplative journeys where he associated memories and imagining to objects in the room: the bed, the dresser, the mirror and various portraits on the walls. His servant asks of one portrait: “How it is that in whatever part of the room one may be, this portrait always watches you. In the morning when I am making your bed, the face turns towards me; and if I move toward the window, it still looks at me, and follows me with its eyes as I go about. (De Maistre, 2002, p. 43).’ The servant is disturbed by this phenomena but De Maistre, meditating upon the problem, sees the original, absent object of the portrait as eternally present in the gaze and the viewer as the sole being she wishes to regard. The portrait bestows ‘its glances around, and smiles on every one alike!’ Those two opposing experiences of the gaze by the servant and master might also represent the hospital patient’s ambivalence to the medical institution and the potential for both trust and suspicion.

⁹ A case study in classic psychoanalysis is used to illustrate a set of theories and ideas, for example Freud’s analysis of Sergei Pankejeff- also know as *Wolf Man* to protect his identity.

¹⁰ Rose Sélavy, named after Marcel Duchamp’s female alter ego.
On her first day of admission she was still feeling a sense of shock. It was only that morning that a consultant had given her the news about a life threatening condition. She had six weeks to live if the treatment did not start immediately. The hospital room was small and from the window there was a view of a brick wall. She had no idea how long she was going to be there, but the choice was clear. If she stayed there was a chance of living, if she left there was a greater possibility that she would soon die.

It was difficult to see the patient at first as she was wearing pink hospital pyjamas sitting in a room the colour of Calamine lotion. Rose had only been in hospital for a short time and had already blended herself with the hospital environment. A pink knitted hat completed her wardrobe as she had already shaved her head in preparation for treatment. The ritual process of hospitalisation looked complete.

‘Rose’, I said, introducing myself, ‘I am Dr Sélavy from the psychotherapy team. I’m Rose too, only with the French pronunciation’.

Rose’s merged state with her surroundings brought to mind Winnicott’s theory of child development and his concept of the False Self, the infant complying with her environment to ensure survival (note to self: revisit D.W. Winnicott’s ‘Playing and Reality’)

We made an appointment to meet, Rose’s pink smile belying her obvious fears.

What is the False Self and can there be a Truer Self? Who is really responsible for the life of the patient (it wasn’t me, it was my false self) and who does Rose Madder really think she is?
Fig. 8: Rose Madder sculpture as a wearable object
The Rose Madder Affect
(It wasn’t me it was my false self)

Fig.9: The Rose Madder affect, digital image, 2017
Fig. 10: *Why Would I Lie?*, RCA Research Biennale, Dyson Gallery, RCA, 2015
The Rose Madder Affect reflected a mismatch of patient and environment and how a newly admitted hospital patient becomes quickly institutionalised and compliant with strong external pressures to fit in with the existing medical system. Rose literally turns pink to mirror the institution’s pink walls, pyjamas and blankets.

![Image](image.jpg)

Fig. 11: Rose madder installation, RCA Research Biennale, 2015

Rose becomes camouflaged, part of a machine, the fabric of the building, even. This reflected my own experience when I was first admitted to hospital. As my red blood cells were failing to develop to maturity in my bone marrow, my mind equally failed to fully comprehend my new situation. Kubler-Ross names this state of shock and denial as the first of the five stages of her Grief Cycle, the well-known model of loss and grief in relation to death and dying: (Kubler-Ross, 1969).  

Denial functions as a buffer after unexpected shocking news, allows the patient to collect himself and, with time, mobilise other, less radical defences (p. 52).

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11 On Death and Dying was Kubler Ross’s seminal book in which she propose several psychological stages involved in the process of dying: denial, anger, bargaining, depression and acceptance.
Although now widely seen as an outmoded model, a more fluid version of the grief cycle is still useful in thinking about the process of loss involved in hospitalisation and the effects of serious illness. Kubler-Ross herself revised her theory to clarify that the stages were not necessarily linear and that they could happen at various times of the process, perhaps a transition or transformation of states that are experienced as more staccato and fragmented. There is also an intrinsic assumption in the Grief Cycle concept that one, single framework can be applied to all psychological experiences regardless of cultural, racial or social differences.

I was initially interested in how the medical institution affected the hospital patient and how this might reconfigure ideas of self and identity and my writing at the time made use of Winnicott’s idea of a False Self (Winnicott, 1971). Here is an excerpt from an early draft of my thesis:

The child psychoanalyst DW Winnicott placed importance on the child and mother/parent relationship in early development. He suggested that if the demands of the environment were too unrealistic or too hostile then a False Self develops at the expense of what he termed the True Self: ‘The false self is built up on a basis of compliance. It can have a defensive function, which is the protection of the true self’ (December 2014).

The concept of the False Self initially resonated with my own initial hospitalisation when faced with the dynamics of the (mother) institution and the (child) patient having to adapt to the greater needs of the medical institution. However, I have since rejected the concept of the False Self and the idea that there is a hidden True Self, like layers of self that unpeel like an onion. Can there be multiple, perhaps infinite, selves that are fluid and changeable? I explore this further in Chapter 5.
Fig. 12: Rose Models, digital image, 2015
Rose Madder, my fictional patient, was initially created in response to a problem that developed as a result of my use of my own experience in the research. Early on I found the process of writing about and presenting my experience of illness as too personally exposing. The fictional character of Rose facilitated a distancing from my own traumatic hospital experience. In the tradition of psychoanalytic writing I created a case study of Rose that tells her story through the classical vignette that traditionally functions to demonstrate a wider theory or set of thoughts and ideas. This was initially useful as I was able to give Rose a fictional freedom so that her story had the potential to take any number of directions. Rose could be staged and manipulated like some helpless Freudian puppet, like a Little Hans or a Wolf Man or a Dora. As a figure with no eyes, no ears, no mouth, she was a model that represented the patient as an idealised and mythical universal patient (fig. 12). With no voice and no vision she was a victim of the system and a weak figure in the world on which we can project our fears and anxieties around illness and mortality.

As my research developed it shifted away from the medical and the clinical and I questioned Rose’s enmeshment with the institution, physically taking on the geometry of the hospital architecture: a model patient operating within a medical model (i.e. a system that preferences pathology and scientific knowledge). I was interested in how the patient might resist the strong institutional dynamics of the hospital and how art might help facilitate this. If Rose changed her actual form then perhaps she could move more freely and more authentically. As I became more playful in the studio my main questions that arose were: how could the hospital patient, how could Rose, give shape to agency and self-determination, and what role can art play in this? Could it be that Rose as a sculpture, with me performing inside her constricting body, be the real puppet master? I was later to experiment with costume and performance where I, myself, became an embodied Rose Madder– not being like Rose, but being Rose. From this I developed the idea of a ‘Transplant Self’: a self that emerges from a transplantation process and from the DNA of an anonymous donor.
Rose Madder was the first of several such selves. Rose embodied my experience of having become enmeshed with the hospital institution as well as my sense of leaving behind all that I had been before my diagnosis. In the next chapter I look at how I was able to reclaim my environment by transforming the hospital room. I explore more fluid and liberating forms of isolated space through the emergence of another, non-material, Transplant Self called Yellow.
Everything up here is out of the ordinary. The spirit of the place, if I may put it so, is not conventional.
3. Yellow

In Thomas Mann’s epic narrative *The Magic Mountain* (1924) the main protagonist, Hans Castorp, visits his cousin in a mountain sanatorium. He arrives as a healthy young man but before long takes to his bed with a fever. Very quickly he becomes dependent on the doctors, the institution and the community of patients. He remains there, as if under a spell, for seven years. I finished reading *The Magic Mountain* in the summer before starting this research project. Mann’s creation of an idealised and elevated place in the mountains, with its culture of philosophical questioning, seemed a good place to begin to contemplate my own experience of hospital and illness.

My film *Islanders* (fig. 14), a commission for Chelsea and Westminster Hospital (2015), imagines an alternative environment that might offer an escape from a clinical institution and a shrunken, contracted space that prioritises disease and dysfunctional bodily organs. The brief for the project was to make a moving image work to be shown in the accident and emergency waiting room of the hospital with the aim of contributing to a calming environment. I proposed to make a film that imagined a near future, a landscape where the hospital patient could be transported to a serene and calming space. This idea connected with other research projects,
Fig. 14: Stills from film, Islanders, 2015
mentioned in Chapter 2, that have looked at ways of limiting the negative effects of long-term isolation, either by streaming outside landscapes of nature to the patient in their room, or by providing virtual worlds as a distraction.

I made two different trips that influenced the making of the film *Islanders*: one to North America and the other to the Scottish Hebrides. I visited Concorde Massachusetts and Walden Pond where Henri Theroux wrote a memoir on his two-year experiment in living in solitude and simplicity, a meditation on nature and a critique of material society (fig. 15). I began to think about the relationship between the hospital room and other isolated environments: the differences between isolation, solitude, separateness or loneliness.

![Fig. 15: Woods and site of Theroux's Hut, Walden Pond, Massachusetts](image)

In the same summer I made a trip to the Isle of Skye on the north west coast of Scotland, a place where I lived as a teenager. On this trip I gathered still images and film footage of the local landscape. I made knitted covers for triangulation stations (fig. 18). Skye is the largest of the Hebridean islands and, although it has a
population of around 10,000, it is easy to be alone. I visited the ruins of a Broch, an Ron Age stone structure thought to be a dwelling place, and thought of this as a potential hospital space: a small fortress in a place of complete silence and solitude (fig. 16).

In the studio I made cardboard models of what the ideal isolation room might look like. I made towers, places high up that were influenced by the architecture of convalescence of Mann’s sanatorium in the mountains. I made pods and capsules and speculated about futuristic healing spaces, free floating, hovering perhaps over the earth or above another planet altogether (fig. 17).
Fig. 17: Still from *Islanders* film, 2015

Fig. 18: Knitted cover for Triangulation Stations, Isle of Skye, 2015
There were several challenges resulting from the work. The film’s commissioners specified that there should be a limited use of black in the works as this might make patients think of death. In retrospect my use of peaceful and pacifying images may have complied with the idea that the hospital environment should not be disturbing in any way, that the patient should be cushioned from a life threatening condition. The other problem, pointed out to me in a Research Forum, was concerned with the “hospital-like” colours and the neatness of the imagery, which might also reflect a medical, sterile environment. The Kleinian thinker Elizabeth Menzies Lyth (1988), in exploring anxiety in institutions observed the patterns, structures and defences within the hospital system that are organised in order to distance from the unbearable anxiety of working closely with severely ill or dying patients. For example, the organisation of staff shifts and rotas in such a way as to avoid prolonged periods of contact with patients, therefore avoiding any intimate exposure to death and dying.

By illustrating the hospital experience as a kind of utopian ideal I had failed to address the dystopian possibilities. By relying too much on my own biographical material as an ex-patient, I had perhaps been unable to question a wider accepted ‘faith’ in the clinic. The initial focus for my research had been on the hospital isolation room and I now wanted to disrupt this space and dislodge it from its central place. The environment that I had created was not a critique of the clinic, but a representation of its existence. This mirroring of the institution in the work, rather than offering glimpses of freedom, seemed in retrospect to reaffirm a sanitised space rather than opening it up to other, multiple possibilities.

I attempted to address these issues in my next film Dream Sequence (2016), introducing a more unsettled idea of clinical space. I was interested in the medical institution as an ambivalent space, one that provides potentially life-saving treatments, but can also exist as a restrictive, imprisoning kind of place. This dichotomy is explored from a feminist perspective in The Yellow Wallpaper, the 19th
The novel is written as the journal of a woman prescribed by her doctor husband with rest cure after the birth of a child. He rents them a house in the country to aid her convalescence. As the story progresses she is increasingly confined, ‘for her own good’, in an upper floor bedroom decorated with oppressive, yellow patterned wallpaper and with bars on the windows:

The colour (of the wallpaper) is repellent, almost revolting: a smouldering unclean yellow, strangely faded by the slow-turning sunlight (p.3).

This informal imprisonment and lack of any stimulation leads to her preoccupation with the patterns of the wallpaper and to a psychotic episode. She sees a woman trapped in the wallpaper and the doctor eventually finds his wife circling the room on her hands and knees, an image of madness.

In *Dream Sequence* (2016) I attempted to create a fragmented sense of the spaces of illness: lone wolves (animals that kill); landscapes that are both earthly and cosmological; a zooming in an out of micro and macro spaces that are visible to us through the technologies of the microscope and the telescope (19. & 20). I used computer-generated imagery (CGI) to make viruses, pill capsules and water lilies. I imagined a future that could be both utopian and dystopian at different times. I was interested in the notion of landscape having the power to invoke a sense of wonder and existential anxiety simultaneously.

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12 The water lily referenced a Monet poster from an exhibition of his waterlily paintings that was on the wall of one of my hospital isolation rooms. I had a disturbing medicine-induced hallucination in response to the image.
I became interested in virtual reality and in how this kind of technology might benefit the hospital patient. At first it seemed to be able to offer the potential for an immersive experience that could transport a person from their immediate environment through the creation of a new one. There have been some projects where virtual reality has been used to help with health issues, for example SnowWorld, a game to help burns patients with pain relief. There were a number of reasons why I did not pursue virtual reality in my studio work, let alone my limited technical skills. When I tried the Oculus Rift headset I was left with the common side affects of mild nausea and a sense of disorientation. I would say that the technology is not yet developed enough to be viable for use in health environments, although it could be in the future. On the other hand it is possible that robots (or EI: Embodied Intelligence) could have more imminent techno-social potential in future healthcare, for example, helping people with dementia remember, helping stroke patients get dressed or reminding patients to take medication.¹³

¹³ I attended a symposium at the London Science Museum, Robot Futures: Vision and Touch in Robotics (July 2017), where the increasingly technological sophistication of robots was discussed, although still with relatively limited movements and abilities. Two of the speakers were artists working with EI. The installation artist Ruairi Glynn is interested in our interaction with machines and explores the potential for collaborative relationships rather than ones based on a master and slave model. The artist Joey Holder presented a project where she imagines a future of xenotransplantation, the transplantation of cells from animal to human, through a speculative pharmaceutical company called Ophiux.
Fig. 20: stills from Dream Sequence, film, 2016
Dream Sequence (2016) imagined landscapes that disrupt the Cartesian separations of body and mind, past and future, life and death. This idea developed from seeing an installation by artist Rachel Rose at the Serpentine Sackler Gallery (London, 2015). This site-specific piece consisted of two walled areas at the centre of the gallery, each showing a large video work, both separate but interrelated. Around the outside of these spaces were sets of speakers, each one with a sound from the films separated out. The film that interested me most was Palisade, named after the park area across the Hudson River from the city of New York where the film was shot. A woman sits on a park bench smoking a cigarette. In the distance are the high rises of the city with the river in between. A remote camera pans out to the skyline beyond and then in to the smoking cigarette, the smoke, the woman’s skin, the redness of what seems like the interior of her body. Collaged between this footage are historical drawings of a battle of the American Civil War that was fought on the site of the Palisades. Rose links the different inside and outside spaces of the present, the physical realities of the figure in the park, with the social and historical relevance of the site as well as the geological make up of the land - that which lies just under the surface of the park.

I explored this idea of fragmented space in a student research seminar (The Matter of Spatial Narratives, FARP, April 2016) in a presentation titled The Nearness and Farness of Black Holes. This text attempted to capture a sense of some of the fragmented states of mind and spatial confusion I experienced in hospital at times and to link these to the texts and artists I had been looking at as part of my research:

A Black Hole is probably formed when a massive star exhausts its nuclear fuel and collapses under its own gravity. If the star is massive enough, no known force can counteract the increasing gravity, and it will collapse to a point of infinite density. Before this stage is reached, within a certain radius light itself becomes trapped and the object becomes invisible.  

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14 Hallucinations induced by fever or medication. The fragmented and confusing experience of waking from a 10-day coma.

Black holes are of the body, holes that are medically investigated, probed, sliced, punctured.

The virus that inserts attaches and transforms genetic material. Black patches and shadows. The mind/body split.

When he was half blind with old age and the cells of his retina deteriorated, Monet painted the Water lilies with brushes on long extended sticks. Close up to the paintings there are only marks, brush marks that might have no meaning beyond their own reality. Closer still, in the in-between spaces, the little folk have been seen resting upon the lily pads, flickering their tiny wings. But to believe that these little people really exist, the body temperature needs to be above 40° centigrade when at this threshold the fevered brain begins to confuse. At this place there is no consensual reality: a concrete thinking. No symbolism, no metaphor, no space between.

Dreams in the darkness of the night: the terror of the nightmare. Freud’s Wolf Man dreamt: Some white wolves were sitting on the big walnut tree in front of the window. There were six or seven of them. The wolves were quite white, and looked more like foxes or sheep-dogs, for they had big tails like foxes and they had their ears pricked like dogs when they pay attention to something. Freud saw a lone wolf, Deleuze a pack of wolves.

Holes in the memory

Jung’s shadow is everything that exists outside the light of consciousness. Plato’s allegory of the cave: a series of transitions between darkness and lightness, the hidden and the unhidden.

Emerging from a coma and from the darkness a visualisation arises. The body as a map: North, South, East and West. A landscape: rivers, mountains and infinite planes.

Bion’s Matrix.
Laing’s Knots.
Kasumas infinity nets of light and mirrors
Indra’s cosmological net with its jewel at every eye, each one reflecting the other to infinity.
Rhizomes pushing under the dark earth

The transitional object and the transitional space
The space in-between
The potential space
The space of transformation
The space of becoming
We are told that when a star burns out and begins to collapse on itself a massive explosion is triggered - a supernova. A cloud of atoms scatters across the stellar landscape - hydrogen, helium, oxygen, carbon and nitrogen - the ingredients of life, as we know it.

The core of the star forms into a black hole, contracting, condensing, collapsing trapping light and sucking passing objects in through its gravitational pull.

One light year is 6 million miles away.

Our nearest black hole to us is thought to be 1,600 light years away.

This makes the nearest black hole 9.6 billion miles away

On a trip to Barcelona I visited an exhibition that made me reassess the space of the hospital isolation room. A ‘Happening’ from the 1960’s by performance artist Alan Kaprow was reconstructed in an area of the gallery (fig. 23). A space was marked out with screens and tape on the floor and furnished with chairs, a day bed, a dresser and random other objects. Visitors were invited to arrange the space as they wished. In the time spent in the gallery I witnessed several changes to the order of the objects, each rearrangement reflecting the different personalities of the participants.

Fig. 22: Alan Kaprow, reconstruction of Happening, Barcelona, 2014
I initially imagined that this kind of fluid and flexible space could be adapted to the space of the hospital room and the needs and desires of the individual patient at any one time. My concern, therefore, was about maximising ownership of the environment: rather than a room that was prescribed to the patient, it had the potential to be a space that was created by the patient. However, as the focus of my research moved away from the hospital isolation room itself, and increasingly about a space that was freer and less confined by the institution, I became more interested in the room as a platform, or stage, for the patient. Freedom, therefore, might not exist within the bricks and mortar of the hospital space itself, but in the actions and agency of its inhabitants. In this way Yellow, as my Transplant Self, embodied the idea of journeying and having the freedom to be in relationship with ones environment, as if on a quest of self-discovery.

The next chapter, Key, isolates the K from the CMYK. I detail a major shift in my research that moves away from a representation of the hospital experience to more of an exploration of the allogeneic as embodied in my new Transplant Self, Chimera. As in the medical procedure of transplantation, Chimera is a coming together of two similar but different matters and materials and the friction that might arise by the interplay. I consider the multiplicities and pluralities of illness and identity.
Fig. 23: Fragment of knitting, photograph, 2016
4. Key

Ernest Becker proposes that the fear of death is a condition of the modern West and that death in earlier societies was an integral component of the lives of a community. He explains this in two ways: as an effect of the external, that is, that our terror is an existential response to the threats and dangers of a hostile environment; or as an internal, biologically determined instinct, as in Freud’s death instinct (Becker, 2007). Freud suggests in *Beyond the Pleasure Principle* (1991) that the two drives of Eros and Thanatos, or the life and death instincts, are opposing but complimentary. His instinct theories have since been discredited as too unscientific, dualistic and biologically reductionist and Freud himself suggests that his ideas are speculation. Nonetheless, his imaginings on the origins of the instincts provide rich visual material. He writes of small particles of fragmented living substance that instinctually strived.

... and gradually succeeded, as they developed through the kingdom of the Protista, in overcoming the difficulties put in the way of that endeavour by an environment charged with dangerous stimuli—stimuli, which compelled them to form a protective cortical layer? and finally transferred the instinct for reuniting, in the most highly concentrated form, to the germ cells?’ (Freud, 1991, p.332).

These kind of molecular images influenced my film *Dream Sequence* (2016), discussed earlier and referred to later in this chapter. Karen Barad, in her paper *Nature’s Queer Performativity* (Barad, 2011), suggests a less binary activity than Freud where the atom operates in queer and unpredictable ways. She suggests that amoebas operate collaboratively as nonhuman agents, manifesting in the formation of swamps and in the popular imagination through films like the 1958 film *The Blob*. These ‘queer critters’, as she describes them, have the potential to overwhelm us, to take over and to ultimately kill us (like a cancer or a virus).

I explored these differing ideas of life and death, dualities and pluralities, in a presentation to my research peer group (FARP, November, 2015) in the context of the fictional patient Rose Madder, who was still stuck in rigid, geometric mode - a
victim to the hospital environment. Having thought of killing off Rose (in my experience alter egos have the potential to become too powerful), I instead imagined two Rose Madders, both with a 50/50 chance of living: one accepting hospital treatment and choosing to live, and the other refusing any intervention and therefore choosing to die. I demonstrated this idea in a test film of overlapping sequences, the beginning of experimenting with a less graphic approach to moving image. For the Rose choosing to live the treatment itself had only 50% chance of working and if the bone marrow transplant did succeed then Rose would have two bone marrows - her own and that of the donor. Would Rose choose to live or die? Was there any real choice in the matter? In imagining a less binary option, a more pluralistic possibility, I considered Rose’s ontological dilemma within a framework of Quantum Mechanics and the concept of Schrödinger’s cat (Gribbin, 2012): a cat in a closed box that is both dead and alive only until the box is opened and the creature can be observed to be either one or the other. If life and death do exist on the same plane and if there is the possibility of an infinite number of parallel worlds to the one that we are experiencing now - is it possible that Rose could be both alive and dead?

It was these ideas that shifted my research to more of a focus on the allogeneic, the medical term for the kind of transplant that combines two different kinds of cellular material: that of the donor and that of the recipient. The process of transplantation involves a literal integration of another’s cellular material and, in the case of a bone marrow transplant, an integration of the donor DNA: the donor and recipient cells combine as a Chimera, the medical term for the fine balancing of cells that keeps the disease in remission. The Chimera is variable and differs from person to person16. The medical Chimera gets its name from a creature in Greek mythology, a hybrid monster with the body and head of a lion, a serpent for a tail and a goat rising from a wound in its back. The image of the Chimera was also interesting to me as a creature that exists not as a binary being, but one with multiple parts. How

16 My own chimerism is currently made up of 99.9% donor bone marrow cells as well some of my own original cells that are undetectable under a microscope.
might this offer the newly transplanted patient a potential for being different in multiple ways?

In the popular imagination there is an anxiety that transplant patients take on the characteristics of their donor. This is explored in an online BBC article that reports on a survey suggesting that some organ recipients believe they have a psychic connection with their donor as well as sharing their memories and experiences.\(^\text{17}\)

The cognitive neuroscientist that led the study states that:

\[\ldots\text{according to one survey of transplant patients, approximately one in three attribute this change to taking on psychological characteristics of the donor even though conventional science has generally rejected the idea that such transference is possible (BBC News, 2009, online).}\]

Thinking about this transplantation of donor personality, however unscientific, I reconsidered my fictional patient, Rose Madder, as an imagined version of my own anonymous bone marrow donor. As I had no information about the donor (sex, age, race or any other identifying information), then the potential new possible imagined embodiments were limitless. It made sense, or non-sense, that these new, donated cells that had taken root in me, enough to change my DNA, could in fact, or non-fact, have become Rose Madder herself. Rose therefore became an imagined self with the potential for multiple identities. If the self is an idea and a construct, or a story, then perhaps Rose could be set free from one singular identity to exist in multiple potentially infinite versions as an assemblage of entanglement. This already made sense by the fact that Rose appears in various, coincidental forms in my research throughout the literature, art and films- like a virus or like new healthy, multiplying cells: Duchamp’s alter ego, Rose Sélavy; a dog called Rose, the companion to the previously mentioned Xavier De Maistre: Gillian Rose’s book Loves Work (2010), a philosophical exploration of her experience of cancer; the work of artist Rachel Rose; the rose pattern that makes up traditional four colour lithographs (fig. 24).

\(^{17}\) A study led by Prof. Bruce Hood, University of Bristol. 20 students were shown photographs of strangers and asked to rate how happy they would be to receive a heart transplant from them. Reactions increased negatively when they were told they were looking at images of ‘bad’ people, and the opposite when shown those of ‘good’ people.
The new direction of my thinking allowed me a freedom in my studio practice where I experimented with still and moving images of myself as the subject of the work. I had initially been reticent to be fully in my work and resolved this by experimenting with face paint and camouflage. For a short experimental film, *Blue, Blue* (2016) I painted my face and hair blue and filmed myself superimposed on separate seascape footage so that I merged with the landscape (fig. 25). I repeated and overlaid the image of myself on top of myself, which gave a less graphic and ‘messier’ effect.

This new shift in the studio work was commented on by one of my student peers in research forum who observed that my previous films had had a cleaner more
graphic style that had perhaps mirrored and re-established the sterility of a clinical environment.

The experiments in the studio resulted in my film Me, Me, Me (2016) (fig. 53) whose title references multiple selves as well as the narcissism of illness, inward looking and self-reflective. For the film I worked with a make up artist whose brief was to ‘make me look beautiful’- although a difficult task as I had a full beard at the time and the result was more androgynous and otherworldly. I then filmed myself, now fully embodied as Rose, and edited out the frames where my eyes were open. This left a staccato, robot like movement, suggesting a state between unconscious and consciousness, sleep and awakening.

At this time I was reading science fiction novels\(^\text{18}\) and writing fictional narratives that imagined a patient of the near future. Alongside this my academic reading was moving away from familiar psychological and psychoanalytic texts to an interest in writing linked to postfeminism, posthumanism and queer theory. Throughout the research project I made sketchbook diagrams that helped me visualise the different links and connections in my reading (fig. 26) and these in turn informed rhizome-like images (fig. 27).

Fig. 26: Four sketchbook diagrams, 2014-17
Through my reading I was interested in whether poststructuralist ideas could help redefine the transplant patient. I explored these thoughts in my studio practice in the context of Rosi Braidotti’s definitions of the posthuman (Braidotti, 2013). Braidotti suggests three different approaches to the concept of the posthuman - the critical, the reactionary and the analytic (p 40) - with her own perspective being the former: a critique of the humanism of the Enlightenment with no ambivalence towards the concept of the posthuman. The reactionary view is the denial that the human is in any decline, the analytic view of posthumanism values science and technology to extend and enhance human life. Science journalist David Cohen defines this last approach further, suggesting the potential for a superior kind of superhuman:

...people who, through genetic manipulation, the use of stem cells, or other bio intervention, have had their ability to remain healthy and active extended beyond what we could consider normal. Their cognitive powers (memory, deductive thought and other intellectual capabilities, as well as their artistic and creative powers) would far outstrip our own (Cohen, 2013, online).

This interested me in relation to the ethics of medical transplantation and how vulnerable this might be to changing socio-political morals and values. And how fragile might the recipient to donor exchange of cellular material be in regards to secondary disease, mutations and malfunctions that have the potential duplicates like a virus or an embryo. Could we, by accident or design, create new and different kinds of monstrous chimeras?
Fig. 27: The Philosophers, digital image, 2016
At this time I was thinking about artists working collaboratively who, like the cells in a donor transplant, come together to create a new entity. I was looking at the *Exquisite Corpse Etchings* of the brothers Jake and Dinos Chapman (Harris, 2010) (fig. 28).\(^{19}\) The etchings show a clear but subtle difference between two drawing styles: one with a slightly softer line and the other a denser and heavier line. The resulting creations are monstrous and vulgar, creatures with single eyes and mismatched limbs, each one with their own accompaniment of grimacing clowns and menacing humpty dumptys.

![Fig. 28: Chapman Brothers, Exquisite Corpse, etching, 2000-01](From: Baker, S. (2005) p.36 Jake & Dinos Chapman: like a dog returns to its vomit, London: White Cube)

It is interesting to compare these with similarly made images that I was looking at early on in my research: Winnicott’s much more benign squiggle drawings created as a playful way of interacting with the children in his clinic (fig. 29).\(^{20}\)

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\(^{19}\) In these works the artists used the technique of the surrealists game where each participant makes a drawing, folding it and passing it on to the next person: a nightmarish distortion of an innocent childhood game. In the etchings there are four clear divisions where each brother took turns to collaborate in making one hybrid image (see Harris, 2010).

\(^{20}\) In the squiggle game one person draws a squiggle and the next person adds to this to make it into a recognizable animal or object. I viewed the original squiggle drawings at the Welcome Trust Library, London.
This reflected the shift of focus of interest and was perhaps also an acknowledgement of the more uncomfortable aspects of my research question: the hospital patient’s struggle for agency and empowerment in the face of the unknown and the unspoken: anxieties about physical and psychological breakdown and, ultimately, the fear of prolonged illness and death.

In the studio I was interested in visually exploring the idea of the Chimera. I took the still image of a wolf from my earlier film *Dream Sequence* (2016) and transplanted a moving image of my head onto this. The resulting image referenced the mythical Chimera (fig. 30) but was also chimeric in the way that it brought different kinds of materials together- still and moving image, print and film (fig. 31). The Chimera also became another of my emergent Transplant Selves.
The image of a wolf/dog has featured frequently in my work and is directly influenced by my time spent on the Isle of Skye in my adolescence walking with my dog in the hills. This emerged in the work I made on my MA\textsuperscript{21} course, as an animal that was half human and half dog, with a canine torso and a human face. The creature was the antithesis to my original canine friend, manifested as a black and nightmarish beast and has had a number of different incarnations in my work,

\textsuperscript{21} MA in Printmaking at Chelsea School of Art, 1986/87.
making a part return now in the form of the chimera. This beast-like creature was also influenced by the well-known metaphor of a black dog that Winston Churchill used to describe his depression. As part of the Grief Cycle depression seems particularly relevant to the experience of serious illness and to the dangerous, life-threatening risk of organ transplantation. In this way the chimera is a signifier of all that is hopeless for the sick person. It embodies the lack of choice in a body that has failed and a fear for the transplant patient that disease will return. Life and death are no longer separate concepts, but exist together. Is death an experience in life, or is it the end of it? The Chimera is not a pedigree animal, or a pure breed, but a Haraway mongrel\textsuperscript{22} and half-breed that is a descendent of the wolves that scavenged from the waste heaps of our earliest settlements.

If the Chimera is an embodiment of similarity as well as difference, however, then it should also have the potential for holding binary opposites as one. The chimera, therefore, must also contain the benign, the relational and the hopeful. At this point in the research I began reflecting on how the chimera might be useful for the hospital patient. The medical chimera can of course be a lifesaver, as it has been for me, but could the chimera-dog-wolf be befriended as part of healing for the transplant patient\textsuperscript{23}? At a critical time in my own recovery, when my donor cells were in the process of grafting, I developed a visualisation practice where I imagined my newly forming blood cell as young pups with each one the colour of different parts of the blood (fig. 32).

\textsuperscript{22} In \textit{The Companion Species Manifesto} (2003) Haraway champions the non-pedigree dog and suggest that they tell us more about our shared histories (human and dog) than the manufactured pedigree (p.88).

\textsuperscript{23} I revisited the Joseph Beuys 1974 performance \textit{I Love America and America Loves Me}, where he travels from his native Germany to New York, and from the airport by ambulance to a Manhattan gallery and returning without seeing anything of the United States. Instead he chooses to spend three days alone with a coyote, for him symbolic of the Indigenous American Indian, making a relationship with the animal and acting out rituals. The performance also took place during the time of the Vietnam War so was also meant to be a reparative gesture.
I thought of this when I attended a symposium, *Artificial Intelligence and the Future of Gaming* (May, 2016), where the idea of an artificially intelligence (AI) in the form of an avatar was put forward as a potential companion that could share life stories, a communication that could be shared with your descendants after your death - indefinitely. Could this kind of collaboration with AI also be useful in combating the
physical and psychological experiences of separation and isolation related to serious illness?

The most obvious other way that the Chimera, as a mixture of donor and recipient cells, is of help to the patients, is through it’s potential for enabling extended life and good health. In the next chapter, Cyan, I consider what methods and ideas might also be of benefit to the patient-artist, or the wounded artist. I chart the emergence of my fourth Transplant Self, Oyster Knife, an embodiment of new life-giving transplanted cells and a vehicle for new and different narratives of illness.
5. Cyan

The name of my third Transplant Self, Oyster Knife, originally came from the title of prints I had made when studying for an MA (figs. 33 & 34) and was appropriated from the essay, *How it Feels to be Coloured Me*, by the poet Zora Neale Hurston. Here she says she feels no sorrow or victimhood as a black woman, instead she feels only her own power and her right to take her place in the world:

No, I do not weep at the world- I am too busy sharpening my oyster knife (Hurston, 1928).

![Image](Fig. 33: Sharpening My Oyster Knife, Lithograph, 1987)

![Image](Fig. 34: Oyster Knife, Lino etching, 1987)

This is a knife, after all, that is meant for prising oysters from their shells and is therefore made from tough material. It is an object that can act as a weapon to be used in defence, if necessary. Oyster Knife as a Transplant Self is therefore an embodiment of this sense of empowerment that might be needed to survive illness and as well as the medical institution. In the cancer world there are frequently used images of struggles and heroic journeys intended to empower the cancer patient. Susan Sontag critiques the use of this kind of metaphor in *Illness as Metaphor* (2013) and suggests that it is not helpful in facing the reality of serious illness and disease:
Since the interest of the metaphor is precisely that it refers to a disease so overlaid with mystification, so charged with the fantasy of inescapable fatality. Since our views about cancer, and the metaphors we have imposed on it, are so much a vehicle for the large insufficiencies of this culture, for our shallow attitude towards death, for our anxieties about feeling, for our reckless improvident responses to our real “problems of growth,” for our inability to construct an advanced industrial society which properly regulates consumption, and for our justified fears of the increasingly violent course of history (p. 87).

The alternative to this mystification of illness, I would suggest, would be new and different kinds of narratives of illness. Arthur W. Frank in *The Wounded Storyteller* (2013) suggests that modern medicine is limited in helping patients to adjust to the new narratives needed for their post-illness worlds: that there might be more to their experiences of illness than the medical story can tell. Frank proposes that before modernism and the invention of the clinic, there was little understanding of what illness was: people went to bed and they died. The rise of western medicine and specially built environments took the experience of illness outside of the home and into the hands of trained professionals. This new medical narrative came to dominate all other stories of illness:

The story told by the physician becomes the one against which others are ultimately judged true or false, useful or not...The ill person not only agrees to follow physical regimens that are prescribed; she also agrees, tacitly but with no less implication, to tell her story in medical terms...The physician becomes the spokesperson for the disease, and the ill person’s stories come to depend heavily on repetition of what the physician has said (p.5).

In the documentary film portrait of Donna Haraway, *Storytelling for Earthly Survival* (Terranova, 2016), Haraway discusses the need for other narratives than the mainly masculine ones that we have inherited historically. These stronger stories need to be weaker so that weak stories can be stronger. Similarly, the voices of medical experts that frame the experience of the sick within one narrative, one truth, need to be quieter so that multiple, and potentially infinite, other stories can be heard. In this way it is possible that stronger patient-artist voices can redefine binary definitions of what is weak and what is strong.
As an antidote to the strong voice of medical science, Frank prescribes three new types of potential alternative narratives: The Chaos Narrative, the Restitution Narrative and the Quest Narrative.\textsuperscript{24} The Quest Narrative has been useful in understanding my reasons for undertaking this research project and spending a significant amount of time making work about my illness. On reflection, I understood this more clearly in relation to what Frank calls ‘automythology’, an aspect of the Quest Narrative that draws on the metaphor of the Phoenix, reborn and rising from the ashes. In this sense, the motivation for this project was to reengage with my art practice, but also to reinvent myself as a different kind of artist. In this regard Frank says that ‘The genesis of the quest is some occasion requiring the person to be more than she has been’ (p.128). This is literally true in terms of my new donor cells, but also conceptually through my performances as multiple Transplant Selves. Frank, however, warns of the risks of the Phoenix metaphor as a kind of denial and lack of integration of pre-illness selves. Something of this nature played out in a development in my studio work in relation to the emergence of Oyster Knife, my third Transplant Self.

I visually experimented with how Oyster Knife might look, filming myself with blue painted face, wearing hospital pyjamas and a hat (fig. 35). In retrospect I would say that the resulting film, \textit{Oyster Knife} (2017) was too illustrative of an idea and too driven by the texts I had been reading at the time.

\textsuperscript{24} Frank recognises that these three Narratives are devices for listening to stories of illness. These can be interchangeable within a story but also not exclusive of other potential narratives (p.76).
Several other artists’ work seems more relevant to Frank’s ideas of the wounded storyteller, and to my appropriation of this in the form of Oyster Knife. The artist and filmmaker Derek Jarman’s film *Blue* (1993) shows one single shot of a blue screen with Jarman’s voiceover describing his experience of losing his sight as a result of his AIDS related illness, seeing only occasional flashes of blue. I was also interested in the art collective General Idea (Bonnett, ND) and the work that they made in response to the AIDS crisis. Their founder member, AA Bronson, survived the other members who died from AIDS related illness, and continued to make work as an artist, shaman and healer. Bronson’s installation and performance pieces convey this experience of having being affected by death through images that reflect spirituality, rebirth and transcendence (fig. 36).
In thinking about these artists, I reconsidered my earlier film *Blue, Blue* (2016) as a more relevant work than the Oyster Knife film in embodying the sense of this new Transplant Self. If Rose Madder signifies the hospital patient as victim of the system, then Oyster Knife encapsulates both the reimagined and life giving newly transplanted cells and as the potential for new identities. In *Blue, Blue* (2016) (fig. 37) there is a doubling of the image of my profile that can be seen to offer more than one possibility with the potential for multiplicity (fig. 37). Whereas the original Oyster Knife from my print of the same name was yellow in colour, this new version is primarily blue. So Oyster Knife can also embody qualities of fluidity, and difference like incarnations of Buddhist Bodhisattvas or Hindu gods. Oyster Knife is therefore multi-coloured, slippery and elusive and cannot be tied down or categorised or medicalised. Oyster Knife personifies the potential of the patient-artist to be other, variable, multi faceted and ultimately self-determining.

The hospital patient is given a temporary, medical self and this can challenge and disrupt former identities. Medical diagnosis creates a fixed self with body functions and dysfunctions fitting into pre-existing medical systems and categories. I was interested in how this rigid notion of a patient-self might be disrupted by more fluid ideas of self and identity. I attended two events that offered new ways of
considering the construction of self: *Storytelling the Self, A Symposium* (Brighton University, March 2017) and the *Voicing Experience* conference (Sussex University, June 2001). From this I understood the posthuman idea of self to be more of a collage of selves: an assemblage of separate images that when put together make up a new whole.

In this context the artist-patient can therefore embody a multiplicity of identities: Rose, Chimera and now Oyster Knife as Transplant Selves are all parts of me, re-imagined from my anonymous donor cells. These new selves might not necessarily be harmonious or a pure reinvention of self. They can be thought of as an identity where parts might be in conflict with each other, with slippages and fractures between self and self - or selves and selves. I explore this idea of diffractive and relational selves further in the next chapter.

![Image from film Blue, Blue, 2016](image)

The two conferences I attended also helped clarify the use of my own artist-patient voice and also highlighted some of the issues of an autoethnographic approach. Autoethnography, the use of personal experience to understand wider culture concerns, can be thought of as too biased in its single point of view, too narcissistic and grandiose. On the other hand it can help understand and share the story of the
individual. An autoethnographic model can debunk the idea that there is one master narrative that speaks of one universal truth:

... the narrative turn in the human and social sciences has triggered a shift from a single, monolithic conception of what should constitute scholarly work in favour of developing pluralism...this pluralistic agenda has resulted in the recognition and promotion of multiple forms of experience in diverse research and representational practices (Grant, Short & Turner, 2013, p.3).

When I began to use my own image in my work, firstly in my film *Blue, Blue* (2016) and then as Rose in *Me, Me, Me*, (2016) the research became more about my own story of illness and hospitalisation. Alongside this visual work, I began to develop my fictional writing from the perspective of my Transplant Selves. As I consider these Selves as all parts of me, re-imagined from my anonymous donor cells, might it make more sense that my methodology is a disruption of autoethnography? Could it be, as my supervisor has suggested, that by offering a non-heteronormative version of the artist-patient that my methodology is more of a queering of autoethnography?

Another version of the autoethnography, and one not so linked to the sciences and to the language of medicine, is Arthur W. Frank’s concept of self-storytelling. Frank emphasises the importance of the telling of stories as part of the healing for those that are sick. He explains in his preface to *The Wounded Storyteller*:

Seriously ill people are wounded not just on body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away. The voice speaks the mind and expresses the spirit, but it is also a physical organ of the body. The mystery of illness stories is their expression of the body: in the silences between words, the tissues speak. (2013, Preface, p. xx)

In thinking about the voice of the patient, I visited an exhibition at the Hunterian Museum at the Royal College of Surgeons, London (*Transplant and Life*, Wynne and Wainwright, 2017). It was useful for me to see an art project that was linked to

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25 Queer theory offers a lens to look at accepted historical norms in relation to gender, sex and sexuality. I utilise this methodology further in Chapter 8.
medicine by its location, but physically separate from the institution of the hospital. The exhibition filmed patients who had had organ transplants telling the stories of their illness and showed the talking head images amongst the museum displays of surgical paraphernalia in glass cases (fig. 38). This juxtaposition of the medical and patient voice seemed to capture a chimeric-like installation of two quite different narratives: the potential of art to question and challenge accepted norms so as to be able to offer the possibility for change and something different.

![Fig. 38: Transplant and Life, Exhibition, Wainwright and Wynne, Royal College of Surgeons’ Hunterian Museum, 2016](http://www.artsandhealth.ie/2017/02/25/transplant-and-life-exhibition-exploring-lives-of-organ-transplant-patients-uk/)

The issue of sound was a concern when I was making my films. Coming from a background of making prints, I struggled with the additional dimension of sound. It seemed important to somehow include the voice of the wounded artist so as to help challenge the more dominant voices in medicine.

The following chapter, *Sound Performance Transcript*, is a departure from the more traditional format for an academic thesis, a shift in the expected narrative. The text is a collage of fragments of my fictional writing, influenced by my hospital isolation
room diaries and sketchbooks that documented my dreams, nightmares, hallucinations and imagined futures. The transcript is an interactive dialogue of four voices that correlate with the Four Transplant Selves of my first four chapters. This script is the basis of the sound piece that accompanies my installation *Curtains* (fig. 53) where I recorded my own voice as each of my Transplant Selves.
6. Sound Performance Transcript

Performers:
C (Oyster Knife)
M (Rose Madder)
K (Chimera)
Y (YELLOW)

Setting: The near future where medical institutions have been replaced by a new kind of healthcare. Private enterprises provide personalised interventions for the client in their home environment. One of those, a company called YELLOW, has secured a bid to help combat newly identified instances of client loneliness and isolation. For this purpose YELLOW has created a wide range of bespoke services, such as: virtual walks in local beauty spots for the housebound, cellular updates direct from a medical hub and companionship in the form of non-human avatars.
### Welcome to YELLOW.

I am your host and guide for today. I hope your journey here was pleasant.

<table>
<thead>
<tr>
<th>Pyjamas</th>
</tr>
</thead>
</table>

| A view of the park |

| Make yourself comfortable |

| (A slow background a rhythm) |

| Hum |

| Hum. |

| Wolf howl |

| Affecting |

| Getting inside |

| Taking me apart |

| Hum |

<p>| (Stop) |</p>
<table>
<thead>
<tr>
<th>The home of your dreams.</th>
<th>Water lilies</th>
</tr>
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<tbody>
<tr>
<td>Little folk sit amongst the pads and flutter their wings.</td>
<td></td>
</tr>
<tr>
<td>Relax and breathe</td>
<td>Blink, blink, blink</td>
</tr>
<tr>
<td>Breathe in breathe out breathe in</td>
<td>I open my eyes</td>
</tr>
<tr>
<td>The air rushing into this one moment</td>
<td></td>
</tr>
<tr>
<td>By and by</td>
<td></td>
</tr>
<tr>
<td>A chimera sits high on a hill.</td>
<td>Darkness</td>
</tr>
<tr>
<td>A distant bell ringing</td>
<td></td>
</tr>
<tr>
<td>Remembering India</td>
<td>Bell</td>
</tr>
</tbody>
</table>
It’s me… I have my hand on your middle

Am I?
Who am I?

How are you today?
I’m Ok

How are you feeling?
I am two

Yes, I am two

(Chanting)
No eyes, no ears,
No nose, no tongue,
No body, no mind.
No seeing, no hearing,
No smelling, no tasting,

Nothing seen, nor heard,
Nor smelled, nor tasted,
Nor touched, nor imagined

Bell
Bell
Bell
Bell
Bell
Bell
Bell
Bell (life support machine)
Beep
Beep
Beep
Beep
Are they you?

Breathe in
breathe out
breathe in

Darkness again

A cinematic close-up of moving lips

Everything should be said without words

I am the colour of the sky on a summer day.

My body is made of deep blue light

A pastel blue lotus flower, of an extraordinary delicacy

(Chanting)
CMYK CMY CM C
MYK MY M CYK
CY Y CMK MK
CK YK K CMYK
CMY CM C MYK
MY M CYK CY Y
CMK MK CK YK
K CMYK CMY CM
C MYK MY M
CYK CY Y CMK
MK CK YK K
CMYK CMY CM C
MYK MY M CYK
CY Y CMK
The moon, the blue moon, the white moon, the moonlight, the moonlit sky.

Living and dying, living and dying, living and dying.
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7. CMYK

Having brought my Transplant Selves together for the *Sound Performance Transcript*, in this chapter I seek to deliberately and accidentally disrupt and queer the categorisation of traditional CMYK printing. I consider how these colours might be set free from categorisation as a way of further liberating the wounded artist from normative institutions.

As a result of my research I have rethought ideas around self and identity. Similarly, as a printmaker I have become open to working with film, animation and performance and as a result am less trapped by one artistic identity. Having experimented with moving image and learned how to use filmmaking and editing software, I was now interested in returning to the print studio. As a printmaker familiar with working across all of the print mediums, I missed the different kind of choices and possibility of print. I also felt a need to work with material that was more tactile. In coming back to print after experimenting with other mediums, I began to use print less as a way of making editioned copies of an image. Instead I have thought of the process more conceptually as a method of exploring the ideas relevant to the research, perhaps more akin to drawing or working in sketchbooks.

In both of the print projects that I describe in this chapter, different unforeseen variables occurred to cause a different trajectory in the printing process. This interested me in relation to similar shifts that can happen as a result of the glitch of illness and the unpredictable outcome of organ transplantation. In an allogeneic bone marrow transplant from an unmatched donor, rather than from oneself (autogenic), it can be preferable to have a degree of mismatch of genetic material. This element of genetic mismatch between the cells of the host and those of the

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26 ‘Trapping is the intentional overlap of colours in a printed project that prevents inevitable printing errors from showing. It is compensation –in advance of production–for the human and mechanical errors that result in misregistration of images on a printing press’ (Lawler, B.P., 1995)
donor can help the graft ‘take’. (My supervisor suggested it was like two smooth surfaces needing sandpapering to be able to stick). I was interested in how these different cellular materials combine symbiotically and the emerging frisson, a third element, can be important for their eventual co-existence. I have thought of this mismatching in relation to a number of different areas of my research: the combinations of differing materials and methods in art practice; the multiple ways of thinking and working as an artist; the fluidity of self and the co-existence of struggling identities; illness itself as a glitch in the biological system, a conflict between body and functionality; the potential for mismatch of patient in terms of space, culture and identity.

Some of these themes emerged in my print project: Chimeras C, M, Y & K (2018). This work was initially inspired by illustrated cards of pedigree dogs that I found in a junk shop in Hastings, the type that were included in packs of cigarettes (fig. 41).

Fig. 41: Borzoi, cigarette card, 193

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27 If the donor and recipient (patient) cells are too identical there is a risk of the graft failing. In the early stages of allogeneic transplantation a complication called Graft Versus Host Disease (GVHD) can occur where: ‘Some of the donor’s immune cells recognise the patient’s own cells as foreign and attack them. If (GVHD) is present but not severe, it may be beneficial in helping kill off leukaemia cells’ (Kenyon, ND, p.108).

The cards were mass-produced using traditional CMYK lithography printing and the rose printing pattern can be seen under a magnifying glass (fig. 42).

I wanted to rethink these card images in relation to Donna Haraway’s text, *The Companion Species Manifesto: Dogs, People and Significant Otherness* (1993). Haraway writes about the commodification of dog breeding, our companion species, and the importance given to the pedigree over the everyday ‘non-registered’ and uncategorised dog:

> What should I call the categorically unfixed dogs, even if I stay only in America? Mutts, mongrels, All-Americans, random bred dogs, Heinz 57, mixed breeds, or just plain dogs? ...I cannot begin to plumb the histories of all the sorts of dogs that fit into neither functional kind nor institutionalized breed (p.88)
I wanted to disturb the pedigrees of the dog cards and to create new chimeric categorisation - in a similar way to my questioning of medical systems.

The artist Mark Dion in his exhibition *Theatre of the Natural World* (Whitechapel Gallery, 2018) appropriated the classification system of the museum to create alternative display cabinets whose drawers were filled with rows of plastic flotsam found by the side of the Thames. He rearranged these pieces of discarded rubbish in

Fig. 43: Selection of Dogs & Chimeras, digital image, 2018
groups of the same colours: the more expected specimens from the natural world replaced by the very things that now threaten to destroy it.  

Similarly with the *Chimeras* print project I wanted to use the trope of the collectors card to re-represent pedigree as a twisted and dysfunctional, performing very differently from that expectations from a pure breed. The *Chimera* images went through a number of different stages before it reached its current incarnation (fig. 43) (This development is described more fully in Appendix 3). At one point I was planning to make a book and one of the print tutors had suggested a ‘pas de deux’ book, a format where the reader turns the book upside down and back to front, and starts again from the other side. I have recreated this concept over the following twelve pages (fig44). In a hard copy version the text can also be looked at upside down and from both sides. In this way the dogs that meet in the middle become contorted, mismatched versions of their original pedigrees.

29 Artist Andy Holden reimagined the systems of ornithology and the practice of egg collecting in his exhibition *Natural Selection* (2017).
Fig. 44: Pages 1-12 of chimera dog book, 2018
What interested me about the process, was the potential for the print idea to manifest in a number of possible ways: large prints, miniature prints, a stop-frame film and a book. I have thought of this in relation to my research question of how the artist-patient might perform differently from that which is prescribed. Can art help free the artist-patient from the institutional norm and, if so, what is the nature of the new and different kind of performance?

When I was planning to make prints of the *Chimeras* for the RCA Research Show (*Flight Mode*, 2018) I had initially envisioned them printed on a large scale. As a printmaker I had always made large prints as a way of challenging the traditional scale of print and this was my default position. However, because I was unable to access the print workshops at the right time, another kind of glitch, I had to rethink the format. I chose to print the four images true to the original small scale of the cigarette cards (fig: 45). This meant that the resulting four prints were unusually small and proved problematic in exhibiting alongside other larger and more dominant works. This is interesting to think about in the context of my discussion in Chapter 5 about the need for the voices of the weak, or the small, to be heard. The scale of my prints meant that I had to be proactive so as not to be overlooked and marginalised in the exhibition space. The feedback from my supervisor after seeing the exhibition was that the strength of my work might have been in its smallness and in the fact that I had four pieces of work to the others one or two. At the time of writing I have made a proposal for a site-specific work that would involve printing the *Chimera* images large enough to fit a billboard, so taking the idea to another extreme.
For another print project I worked in lithography. It was a technique I had not used much before and I was interested in how the process of using oil and water might relate to my thinking around the chimeric. In his technical manual on lithography Vicary discusses the balance of the oil and water elements of lithography and asks:

Can the water-rejecting properties of the one be strengthened without diminishing the grease-rejecting properties of the other? Or vice versa? (Vicary, 1976, p. 31)

I was interested in how seemingly different substances and materials work together in a chimeric balancing. I started the print project by making a digital image of a self-portrait that was a hybrid of my Transplant Selves, Rose and Oyster Knife (fig. 46).

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30 As a printmaker I have always been curious about materials that resist each other but also work together: etching inks of different viscosities that create new and unexpected patterns; linoleum printed on top of screenprint (as in the Oyster Knife print discussed in Chapter 4, fig. 29). This has developed in my research through experimentation with still and moving images, performance, and written and spoken word.
I worked on a machine operated lithography press helped by a print technician. Despite a clear plan to begin with this printing method proved complicated and as a result we accidently used one of the four colour plates twice (see Appendix 4 for more details of the printing method). This radically changed the intended colours of the finished print and created a new, accidental image (fig. 47).
Rather than making an edition of identical prints in the traditional way, I created a series of images from all the possible combinations of the CMYK colours (fig. 48). I later made this into an animated print and used this for the final version of my chimera film (fig. 31).
Fig. 48: Allogeneic Selves, 14 Lithographs, 2017
The glitch as an anomaly of the predicted or predestined result, gave the potential for a multiplicity of possibilities. A queering of the four colour printing process enabled one colour to become another. So, in this case Rose could potentially be blue and Oyster Knife could be pink: a non-binary mix up of the colours traditionally associated with girls and boys.

This unintentional mistake in printing interested me in relation to my thinking around illness as a glitch in the system. It was as if a virus had invaded the printing process. The printing mistake was also a failure in my attempt to categorise and fit ideas into boxes. My framing of the first four chapters of this thesis with the individual colours of CMYK was useful in capturing the disparate ideas and methodologies of my research. This separating out was also helpful in understanding the individual entities, a kind of mimicking of a medical categorisation that isolates biological parts. In retrospect, this division of colours in the lithograph seemed binary and prescriptive. This gives an impression of my Transplant Selves as separate from each other, existing as unconnected entities. Could it be, instead, that these newly emerged selves are more slippery and elusive? That these selves are not so easily isolated and separated out into medical systems? Is it also conceivable that these Transplant Selves can be more relational and multi faceted? Where Rose Madder and Oyster Knife were singular stories, the Chimera was a hybrid of selves that began a conversation about plurality. In what way can the individual colours of CMYK, the individual entities of my research, begin to speak to and with each other? How can these entities, that I have taken apart in order to study in isolation, come together again?

The next and final chapter seeks to answer these questions by drawing on queer and feminist ideas of performativity and self so as to develop the idea of an alternative medical theatre, a platform for my four Transplant Selves to perform differently in a new configuration of interrelating.
8. Performance

When I began to explore the idea of performance through my films, particularly as Rose Madder and Oyster Knife, I was directed by my supervisor to The Old Operating Theatre Museum that was part of the original eighteenth-century St. Thomas’ Hospital in London Bridge (fig. 49).

Fig. 49: The Old Operating Theatre Museum, London Bridge
(My own photograph, taken November 2017)

Here, medical students and members of the public watched live operations and procedures. With the introduction of chloroform as a sedative, the patient could now be observed as an isolated and unconscious body. Foucault talks of this medical ‘gaze’ in his critique of the medical institution, The Birth of the Clinic (2003):

So many powers, from the slow illumination of obscurities, the ever-prudent reading of the essential, calculation of times and risks, to the mastery of the heart and the majestic confiscation of terrible authority, are just so many
forms in which the sovereignty of the gaze gradually establishes itself- the eye that knows and decides, the eye that governs (p.108).

So in considering the role of the hospital patient as passive and unconscious, how can a different kind of theatre, and a different kind of performance, help the artist-patient resist the authority of the established medical institution in a more conscious way? I have thought of this in relation to Postfeminist and queer methodologies that rethink traditional roles associated with gender, sex and sexuality.

In Gender Trouble (2006) Butler argues against the notion that gender is fixed as a category and has only one universal truth. She suggests that gender is performed from birth and that this ‘performativity’ is the repetition of inherited ideas of what is normal: that male and female identities are acted out in response to the effects of those around us. James Ravenhill describes this kind of performativity in regards to his sexuality in an anecdote about his car breaking down:

... the rescue service sent along this good-looking, 30-something man to help: a knight in fluorescent armour. The car was fixed promptly, but as I headed home, I couldn’t stop thinking about my interaction with this guy. Why had my voice dropped by an octave as I described to him what has happened? Why had I talked about the names of car parts that I knew nothing about? And what was with that feeling of blind panic when he asked me to “try and turn her over”? (Gscene, 2017, p.39).

I would say that these, mainly unconscious, adaptations to a heternormativity are the default position of the everyday queer experience. It is interesting to think of this in the context of shared spaces, like the medical institution.

The poet Audre Lorde in The Cancer Journals (1980) writes about the institutional expectation for her to conform to a certain idea of womanhood after her diagnosis of breast cancer:

As a 44 year old Black Lesbian Feminist, I knew there were very few role models around for me in this situation, but my primary concerns two days
after a mastectomy were hardly about what man I would capture in the future…(p. 57).

She goes on to describe how she was strongly encouraged to wear a prosthesis after her surgery and the consequent disapproval she experienced by choosing not to have one. A nurse suggested that she could at least wear something when she visited the aftercare clinic otherwise it would be “bad for the morale of the office” (p. 60).

In my own hospital stay I experienced a kind of queer reversal of Lorde’s situation when a nurse referred me to the ward’s wig service. I had playfully asked if men could access this provision, usually meant for female cancer patients who had lost their hair through chemotherapy. The genuinely respectful way that I was able to choose and was fitted with a long, blonde wig affirmed that I could be free from the tyranny of how I was expected to look, dress or behave as a man. On reflection, it was also an act that acknowledged a queer history of transgression of gender roles and, for me, a political statement. Butler states that:

No one really performs a gender alone, no matter how beautifully idiosyncratic the performance might be. That does not mean that everyone is performing it in the same way- not at all. But even under conditions of extreme isolation, the kind that follows from performing gender in ways that are considered non-normative in highly hostile spaces, one suffers alone, but there is always the shadow of company, of others who would be treated the same way were they present. One finds oneself inside a category of one’s own making (Butler, ND).

So how can the artist-patient create ‘a category of one’s own making’? A few days after Rose Madder came into being, I made a chance discovery in the library of another Rose, Rrose Sélavy. Here, in a series of black and white studio photographs by Man Ray, Duchamp’s Rrose poses in a fur coat and broad rimmed hat (fig. 50). For its time this was a playful but radical performance that created a queering of gender expectation.
Butler suggests that accepted categories of gender could be brought into question through other kinds of performativity, for example the performance of a drag queen where female-like attributes are acted out. Dressed as my own Rose in *Me, Me, Me* (2016), the moving image literally shudders as if embodying a dissonance of difference. On reflection, this kind of mismatching in editing can be thought of in the same way as mismatches of gender, sex and physiology against the prevailing social norms. In his introduction to *Queer* (2016), Getzy defines queer as ‘an attitude of defiance that has arisen again and again in response to the operations of
power that police difference and that exile the otherwise’ (p. 12). So not only is queer a debunking of the narratives of historical norms, it is also a radical and proactive challenge to the status quo.

I attended a lecture given by Jack Halberstam (RCA, 2018) who discussed the work of a Canadian artist Kent Monkman who paints from a queer and anti-colonial perspective. Monkman is from Cree ancestry, a community that values what they call ‘two spirit’ people, or those that are intersex and are neither male nor female. In the painting Seeing Red (fig. 51), made for Canada’s 150th ‘birthday’, Monkman depicts himself as his ‘drag avatar’, Miss Chief, in a scene that re-narrates an original meeting of the indigenous people with the Canadian colonialists.


This encounter, reimagined through a queer lens, questions the accepted power differences through the powerful central figure of Monkman as a queer, matador warrior.

In my own work I have thought about how these postfeminist and queer notions of performing differently can be a catalyst for change. In bringing together my writing, both academic and fictional, and my films and sound piece, I wanted to create
another way of thinking and looking at the experience of illness in the medical institution. I had sharp reminder of what it was that I wanted to change when I was writing this final chapter. As a result of what turned out to be a minor eye condition, I had to make a visit to an Accident & Emergency drop-in service. On my arrival I was signposted to three different reception desks, asked to fill out forms and told to take a seat. During the two-hour wait I found myself becoming increasingly constricted by the situation, unable to physically move in case I missed my turn. Undoubtedly I was re-performing a patient identity that was very familiar to me.

Around this time my supervisor suggested I visit John Walter’s exhibition CAPSID (fig. 52). For this show Walter had created an immersive environment with floor to ceiling drawings, paintings video pieces and it is as if the viewer is brought into the space of the artist’s mind.
He shows images of Duchamp as Rrose Sélavy, the HIV virus, pill capsules and homoerotic drawings in wild fluorescent colours that help create the sense of being trapped in some nightmarish nightclub. Walter also, however, uses this queer aesthetic to offer an alternative medical environment that helps generate new conversations around HIV infection and it’s social and psychological affects.

Visiting Walter’s exhibition confirmed the importance of the artist’s need to form other modes of understanding illness and to create different narratives from that of the medical. For my final work of this project, *Curtains* (2018)(fig. 53), I brought
together four of the key films of the research\textsuperscript{31} along with my Sound Performance Transcript (Chapter 6). This installation, exhibited in a room the size and shape of a hospital isolation room, sought to decentralise and dislocate the original medical space. In this way my disparate selves, Rose, Chimera, Yellow and Oyster Knife, spoke and performed together in a divergence from the given script of the sick role\textsuperscript{32}, and as an experiment in a new and different way of performing from that of the medical.

\textsuperscript{31} Four films: Islanders; Blue, Blue; Me, Me, Me; Chimera CMYK, (figs. 55, 57, 58 & 62, Appendix 1). Soundtrack based on the Sound Performance Transcript, Chapter 6.

\textsuperscript{32} The medical sociologist Talcott Parsons wrote about the idea of illness as a deviance from the norm of health where the ill person is separated from the wider healthy society and given the sick role (NHS England, 2013). Although this concept is now seen as a somewhat binary experience of illness, I would say it is still significant for the patient who spends long periods of time in hospital.
Fig. 53: Images from installation, *Curtains*, 2018
9. Conclusion

I began this practice-led project, *The Patient is Performing as Unexpected*, by revisiting the long periods of time I spent in hospital isolation as a result of my treatment for Acute Myeloid Leukaemia. My hospital sketchbooks and diaries provided useful resources in addressing some of the difficulties I experienced as a long-term hospital patient: a sense of disempowerment that comes from being ill within the contemporary medical institution. This was less to do with the work of the medical professionals themselves, or with the care that they provided, but more a questioning of accepted systems of power and control. I wanted to use my own experience as a patient, therapist and artist to challenge the hospital experience so as to transform the power imbalance between patient and institution. In this way the artist-patient, or the wounded artist, might be free to move, speak and act differently from that prescribed by the medical institution.

In the studio I developed my pre-research work on the theme of the ‘cancer journey’, the idea that illness takes you to a different land and that, while in that place, there is something to learn and to bring back to the world. My research began as a *searching* for meaning in my experience of being ill and took shape in response to Frank’s concept of the quest narrative of illness (2013, p.76). I was motivated to undertake a practice-led research so as to help me understand the effects of my illness and hospitalisation through an exploratory art practice.

As an antidote to the cheerless, sterile medical space I wanted to create new environments that could transform my experience of hospital isolation. As my research became more focussed on the allogeneic, and the phenomena of my bone marrow transplant procedure, my interest shifted to the chimera and the chimeric

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*Sontag describes the same kind of other worldliness: ‘Illness is the night-side of life, a more onerous citizenship. Everyone who was born holds dual citizenship, in the Kingdom of the well and in the Kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place’* (Sontag, p. 3, 2013).
and the idea that two seemingly opposing concepts can co-exist as a multiplicity: the medical appropriation of the chimera alongside its roots as a mythical creature, and the scientific and the artistic. In my film work I imagined landscapes as both a new kind of healing space and as a more nightmarish, dystopian environment.

This idea of the chimera was present in the juggling of my different identities and perspectives: patient, therapist and artist. This can be seen in the structured shapes from my first film *Islanders* that can be viewed as architectural pods, but also as three different kinds of hats, or thinking caps (fig. 53).

![Fig. 54: Still from Islanders, short film, 2015](image)

The four colours in the still from this film, the CMYK of four-colour printing, became the framework for separating out my patient and post-patient identities in the form of my Transplant Selves. These Selves needed to be isolated, conceptually, in order to provide me with models for transforming old identities and trying out new ones. I had to distance myself from my own traumatic experience of illness in order to find the value of my own story and to find my own voice. Although my Selves, Rose, Yellow, Chimera and Oyster Knife, are written about in the third person, they are all
ultimately parts of me, having emerged from the reimagined new cells, new DNA, of my anonymous donor. Within contemporary ideas of the decentred self, the fragmented self, the non-binary fluid self, these Transplant Selves are me. These Selves are also he, she, they and we, freed from the need to be one thing or another and, like the medical and mythical chimera, have the potential for plurality.

In true chimeric fashion, these Selves embody both, all and every element of my experiences of illness. Rose Madder, for example, is a medical prisoner, a victim and a post-human robot, but she is also a survivor and a queer artist-performer. Oyster Knife embodies the uncertainty and fragility of life and, in his most transformed incarnation, is a journeyer, a mystic-philosopher and a fairy34. My Transplant Selves are a response to all that is suppressed by illness and hospitalisation. They are a dramatic, performative reaction to the deadening and anesthetising of the medicalised self: a queer response offering multiple other possible narratives from that of the medical. They are a form of self-storytelling that visualises my experiences of illness.

As print became increasingly decentred from my studio practice, I made new work with moving image, sound, performance and writing. In this way I was able to free myself from the sole identity of artist-printmaker. In disrupting the traditional structure of CMYK printing I was similarly able to imagine how the hospital patient might also be free from the limiting nature of medical categorisation. In this way it would be possible for the patient-artist to perform differently in relation to the institution, to shift the stagnation of illness, to transform the passivity of the medical patient, to challenge the alienation and aloneness that separates out parts: mind, body, relationships, identities.

By bringing the separated out parts of myself back together (the C, M, Y and K) in my final four-film installation Curtains (2018)(fig. 53), I wanted to experiment with

34 Faeries from Celtic mythology appear in the Hebridean landscape in the naming of places, such as fairy bridges and fairy glens. In another way, The Radical Faeries is a worldwide movement of queer activism, spirituality and anarchism established in the USA in the 1970’s.
how this plurality might look, sound and perform. As a body of work, my Transplant Selves came together in a way that I had not expected. Their mutual performing appeared semi-dormant as if they were moving between unconscious and conscious states, in the process of awakening - like multiple, fractured Rip Van Winkles. In some ways this liminal, transitional state summarises the main theme of my research project, as a fusion of different and sometimes opposing elements. The medical chimera, the aim of a bone marrow transplant, is a balancing of old and new cells and therefore a reintegration of new life where before there was only the possibility of death.

One of the main discoveries that emerged from my quest was this theme of regeneration, rebirth and healing and a renewed awareness of life that serious illness can bring. This is also why queer studies became such a significant element of the research as a reflection of a ‘coming out’ and becoming conscious, but also as a connection to the sense of empowerment and awareness of queerness in the face of oppressive social and political institutions. The action group ACT UP, that I was involved with during the 1980’s AIDS crisis, use the slogans silence=death and action=life: a cry for action and change. In a similar way, my research project has been a quest to speak up, to tell the story of my own illness. I have sought to create a platform for a different kind of performance that allows for a deviation from the expected norm, in whatever form that takes.

My research project offers an alternative prescription for the hospital patient. My project is an artist’s manifesto that offers an antidote to the more oppressive elements of the hospital experience. My manifesto proposes that the hospital patient has the right to:

35 At the time of writing the Scottish government has enabled Doctors in the community to prescribe nature, a walk in the countryside, alongside more traditional treatments.
Behave in unexpected ways
Be themselves (plural)
Be wounded
Know that weakness is strength
Be healed
Dream and to waken
Make art, write, think
Live authentically and conscientiously
Exist without fear

My manifesto is a model for those that have also been separated by the isolation of illness and proximity to death. It is a reminder that we all experience illness and live with the knowledge of our own mortality.

My Transplant Selves have helped me discover new ways of working as an artist and to have an art practice as my main post-illness focus. Although this particular quest has come to a conclusion, it is also the beginning of new quests as I go forward with the results of this research. I plan to develop my Curtains installation concept with the aim of embodying my Transplant Selves with more fluidity of movement and voice. I plan to create new platforms in the intersections of art and medicine and to develop new performances that link hospital spaces, galleries and lecture theatres: installations as institutions for the queer and the wounded. I am interested in publishing my work as fictional and academic writing and as an artist’s book: The Transplant Self-Help Manifesto. As an alternative vision, my work aims to be transformative and so needs to be seen, heard and acknowledged by the medical institution that I have critiqued.

At the time of writing, the British NHS is under threat from growing demands and a lack of funding to match. This means that decisions are made that have the potential to negatively affect those in its care. At a time when there are powerful shifts in the world order towards the politics of the strongman and profit over humanity, it seems that there is more need than ever for weaker voices to be heard.
At a time when those that differently from the norm are being persecuted, when queer people are being tortured and murdered globally, it is essential that we challenge and seek to change the institutions that oppress. The actions of those that divide and polarise need to stand aside on the world stage to make room for a different kind of performance that is non-hierarchical, relational with the potential for behaviour that is unexpectedly-chimeric:

*The curtains open...*

*Chimera steps onto the platform,*

*Raises their heads and HOWLS...*

*Now is the time for action...*
Appendix 1

List of Moving Image Films

Fig. 54: *The Rose Madder Affect*, Documentation of Installation and Performance, 2 minutes (2015), RCA research biennale (*Why would I Lie?* Dyson Gallery, RCA)

Fig. 56: *Islanders*, film, 10 minutes, 2015
A commission for Chelsea and Westminster Hospital
Fig. 57: Dream Sequence, film, 10 minutes, 2016

Fig. 58: Blue, Blue, film, 10 minutes, 2016
Fig. 59: Me, Me, Me, film, 10 minutes, 2016

Fig. 60: Oyster Knife, film, 10 minutes, 2017

Fig. 61: Blue Chimera, test film, 10 minutes, 2017
Fig. 62: *Allogenic Selves*, film, 2 minutes, 2017

Fig. 63: *Chimera CMYK*, Film, 7.46 minutes, 2018
Appendix 2

Writing

A Prelude of Colour

A Hillside, high on a Scottish island with a view as far as Ireland, breathing, breathe in the mist and dampness underfoot. A pause and then from nowhere, no where, a kaleidoscopic zooming into colours of wet heather, moss and spring flowers, water and colour - watercolours: Yellow ochre; Cadmium yellow (lemon?); Cobalt blue; Ultramarine blue; Rose madder; Viridian. Elsewhere, in a parallel Punk universe, colours collide, beckoning.

Hospital Diaries

Image of a ying yang pill, black and white on pink, spinning, starting with black fading into image and then fading out to white. Sound of waves.

The Chicago skyline through the slick glass windows of Frazier’s apartment. The rolling Yorkshire Dales, the suburban neighborhood. Spaces in books, other lives, characters, worlds, fictional places.

Packing the bag, pyjamas, notebook, novels, music and medicine. Feeling of dread somewhere in the stomach.

Morden, Streatham, Streatham Common, Denmark Hill. Pizza Express, sports shop, cafe etc.

The smokers in pyjamas and dressing gowns, staring hollowly at me recognising me as a newbie from my bags. Welcome. The long walk along corridors.

The bed as an island within the room, within the ward, within the department within the hospital. Parts of me are physically spread across these spaces- in the lab, the freezer, the ward round in doctors brains and medical notes. I am sent new parts from half way across the world a stranger’s tissue that will soon be part of me, theoretically. I am discussed, diagnosed, prescribed, tested, x-rayed, medicated, weighed, measured, counseled, cared for, kissed, hugged, stared at, observed,

The space is a studio

The park, a cyclist propositions me but I fear his aliveness affecting me, getting inside and taking me apart. Prof M catches me sunbathing on a square of grass, catching the last of the summer sun. He knows I know he sees me and inevitably it gets back to the nurses on my return and I get lectured on the risks of fungus, bacterial infection from earth, the potential of new inner growth, a mossy bronchial
forest, that might suffocate my lungs. Still, for a moment I enjoy a sense of normality, of the freedom to do and go as I please.

Social space. Making it my territory, but it being a private space that is public.

Room, isolation room, ventilation system, pure air.

Bedroom, living room, bathroom, kitchen dining room all the rooms in the house. Six for the price of one.

My blood cells, my neutrophils my...I imagine them as pups, puppies, shades of the rainbow, full of energy and racing, up hills,

Memories of Travelling keeping me going. India, the hill station, the palace, the desert, floating freely down the Mekong River, gently stoned. Driving into Las Vegas, the Grand Canyon, and the expanse of Death Valley.

Future dreams of Skye, parachute jump for charity perhaps, giving something back. Black Cullin Hills, Red Cullins and the Irish Sea beyond.

Dream space, and the negative opposite of the cheerfulness of daily hospital life. Witches, spontaneous combustions, nightmares, fear, thoughts of death

Psychological space with the Macmillan counselor.

The canteen, my birthday party with hats and cups of tea. A homogenised mix of people, doctors, nurses.

The inevitable bad hospital art.

We drive to the sea, park the car where we are not supposed to park, facing the waves, warm inside when it's cold, sitting in silence and drinking the best hot chocolate of my life.

The sketchbooks, spaces in the mind, potential spaces, Imagined space

Talk of the stars and the moons, the planets and their shifting’s in tune with my inner waters.

The sound travelling across space, nurses laughing, beeps, alarms, the scraping of chairs on the floor above. The view of a wall from the window and at a squint the park. The linoleum floor magnolia walls, ensuing. Elevated bed that goes up and down with plenty pillow to be propped up on when sleeping to avoid dying in the night, or to avoid the fear of it at least.

Journey home, jubilation being in a space capsule, everything faster. Morden, Gatwick, Three Bridges, Haywards Heath.
Coma

When she opened her eyes Rose could feel the air rushing past, like her life, all contracting into this one moment. An ecstasy of molecules mingling with the ever-closer rolling vista: the Black Cullin hills, the red Cullins, the outer isles and the Irish Sea beyond.

Dr Selavey came to mind, or at least part of her, a cinematic close-up of her moving lips.

No eyes, no ears,
No nose, no tongue,
No body, no mind.
No seeing, no hearing,
No smelling, no tasting,
Nothing seen, nor heard,
Nor smelled, nor tasted,
Nor touched, nor imagined

Breathe in, breathe out, breathe in.
Breathe out, breathe in, breathe out.

Darkness again, suspended as if floating on air. Like a pupa, encased, waiting. From the dark a tangle of coloured lights, shimmering. Then a voice- “Rose, it’s me... I have my hand on your tummy”. There is a kind of soft sensation where a middle might be.

Is there middle?
Am I?
Who am I?
Darkness.

Eyes opening and there he is, his mouth moving and making sounds that aren’t clear but sounds as if he might be saying:

    everything

    should

    be said

    without

    words
Welcome

Hum
Hum
Hum

Please do make yourself at home
Hum
Hum
Hum

How are you today?
I’m Ok.

How are you feeling?

My body is made of deep blue light, the colour of the night sky in the tropics. My hair is dark and I am dressed in flowing, richly ornamented robes. I sit in the full lotus posture. My whole body radiates light. My right hand reaches down, palm inwards. The tips of my deep blue fingers just touch the white moon matt on which I sit. In my heart is a syllable, made of pale blue light. It is the syllable hum, like the call of a great drum. My mind becomes absolutely tranquil and steady. Each moment lacks nothing; it is complete as it is. Everything is just a perfect reflection in the mirror of my mind. 36

36 Adapted from Meeting the Buddhas (Vessantara, p.71)
Appendix 3

The Making of Chimera Prints in Six Stages

1. Chance finding of a set pedigree dog cigarette cards in a Hastings junk shop:

Fig. 64: One of a set of cigarette cards, Poodle

2. Painted on the cards in an attempt to humiliate the pedigree:

Fig. 65: Painted dog card, Bozoi

3. Created flat images of dogs in Illustrator:

Fig. 66: Vector shape, Borzoi
4. Combined two different dog images to make a chimera dog:

![Fig. 67: Bull Terrier + Samoyede](image)

5. Had an idea for a book that has the technical name ‘pas de deux’: a book where the reader turns the book upside down in the middle and begins reading from the other direction. Made a test book where the two different dog breeds meet in the middle to create a chimera-dog:

![Fig. 68: Borzoi chimera](image)

6. Made a background for the chimera to create a new card that reflected the style and size of the original cigarette card:

![Fig. 69: Chimera K](image)
Appendix 4

The Making of a Chimera Print: Allogeneic Selves

I began by separating out the four basic colours of the image into Cyan, Magenta, Yellow and Key and transferred them photographically onto four individual lithograph plates. The traditional method of four-colour printing in this way usually involves printing one plate on top of the other so that the colours combine and overlap to create most of the other colours in the spectrum. However, as my aim was to experiment with the process of CMYK printing rather than to produce multiple copies of the same image, I chose to print the colours in all of the fourteen possible combinations of C, M, Y and K using either one, two, three or all four plates\(^3\). The resulting pattern acted like a kind of genetic code for the print:

\[
\text{CMYK} \quad \text{CMY} \quad \text{CM} \quad \text{C} \\
\text{MYK} \quad \text{MY} \quad \text{M} \\
\text{CYK} \quad \text{CY} \quad \text{Y} \\
\text{CMK} \\
\]

\(^3\)The idea was also to disrupt the more traditional method of producing multiple identical prints associated with the more commercial aspect of printmaking. This was linked to a previous method I had used in a series of prints inspired by Fibonacci numbers: a sequence where each number is the sum of the two preceding ones- 1,1,2,3,5,8,13,21,34,55, and so on. This mirrors the growth of plant cells and I had been interested in how this might apply to printing.
This image was made in Photoshop with an enlarged grain of 25 dpi (dots per inch) so as to maximise the overlap and mismatch when printing. I also wanted to break up the image a little so that it would be similar to looking at cells under a microscope. The digital image was then separated into separations for four colour printing (Cyan, Magenta, Yellow and Key (black)), and then exposed onto four separate, photosensitive plates. I therefore chose a system where every print could be different by printing the four colours in all fifteen possible combinations. The resulting pattern acted like a genetic code for the print:

Allogeneic Print: Studio Diary

02-02-2017

Visited the lithography studio and spoke to S. the technician. Best option seems to be the Mylander; machine operated usually for editions, but got excited about the possibility/potential of misregistering by:
1. Moving the paper
2. Turning the paper upside down
3. Trying different combinations of colour layers

RGB or CMYK or both?

Meeting with G. technician from moving image. A three or four screen film, possible in Premier Pro by creating a nest so as to work on them together. Talked of deliberately mismatching of four screens. Having them as overlapping projections, or projected into a corner or onto the surface/print, then filming this.
07-02-2017
Digital studio with print technician A.
Rose pattern: smaller dpi (e.g. 25) = bigger pixel; larger (e.g. 300) = smaller pixel and finer image. Zooming into the image= looking under a microscope? Rose Pattern= cell, molecule, atom? Seeing the mismatch.

21-02-2017
Lithography studio with print technician R.
Mylander press.
18 sheets of paper
14 prints that are unique combination4 of an edition of the CMYK

CMYK
CMY
CM
C

MYK
MY
M

CYK
CY
Y

CMK
MK

CK
YK
K
First colour printed- cyan.

22-02-2017

Lithography studio.
Second colour printed- yellow.
Third colour printed- magenta.
Noticed something not right in the image. It seemed darker, more monochrome than it should have. We worked out that the cyan plate had been printed twice- once with cyan and once with yellow. This meant that the yellow did not show in the image.
Fourth colour printed-black.

Image is completely different from the original planned.

01-03-2017

Digital studio, discussion with R.- he offers to print the whole sequence again. I tell him that part of me is interested in the new image almost more than the original and want to think about the need for reprinting. I know there is some meaning in what has happened but not sure what. Also, it might be better to start with new images, more on one sheet and using cheaper paper.

Discussed with A. about scanning the prints into the large format scanner.
Scanned in 5 dog card images at a high resolution: 2400 dpi.

Later realise that the mistake in the order of printing is like a glitch in the system, a mismatch (between technology and art?).

15-03-2017

Scanned lithographs with large digital scanner and uploaded as large files- 300dpi.
Spoke to S. about making a book from the lithographs. She suggested folding the image in half- like this idea.
20-03-2017
Cropped the 14 lithograph images in Photoshop. Emailed R. about printing the original set of prints in the correct colours. Had the idea of making two books- his and hers- bit binary?

22-03-2017
Reply from R. saying that he will print original run of lithographs.
Spoke to A. in digital suite re enlarging the rose pattern in CMYK printing. Talked about having a very large (screen?) print where close up the resolution dot is large and makes up an image when further away.

**Some Thoughts on CMYK**

So Blue and Yellow could represent different selves, Yellow the Yellow Wallpaper from the novel by the same name (Perkins Gilman, 2011). In addition, different combinations of these base colours would have different meanings and affects:

C+M=the chimera
M+Y=the hospital isolation room
B+K= death
C= Oyster Knife
M= Rose Madder
Y= The Yellow Room
K= The Chimera

CMYK- multiplicity:

C=Blue
M=Rose
Y=Medicine
K=Death
C+M=Chimera
M+Y=Hospital isolation room
Y+K=Companion
CMYK- overlapping,

Colours can create all the colours in the spectrum but in terms of making new images- this is infinite...
References

Books, Journals & Online Sources


Tisdall C. (1976) Joseph Beuys, Coyote, Munich: Shirmer & Mosel


Films


Conferences, Symposia & Lectures

Artificial Intelligence and the Future of Gaming, 23rd May 2016, Brighton Festival, Brighton.


Voicing Experience, 15th & 16th June 2017 University of Sussex, Brighton.


Visual Cultures lecture Series: Jack Halberstam- Wilderness, 12th December 2017, Royal College of Art, London.

Exhibitions


